Second COVID-19 Virtual Community Meeting Pre/Post Questions

Did you attend the COVID-19 Virtual Community Meeting on March 27?

- Yes: 83%
- No: 17%

I understand the precautions that I should be taking as a CLL patient during the coronavirus (COVID-19) pandemic.

- a. Strongly agree: 47%
- b. Agree: 31% (Pre), 42% (Post)
- c. Neutral: 11%
- d. Disagree: 1% (Pre), 1% (Post)
- e. Strongly disagree: 0% (Pre), 0% (Post)
I understand what I should do if I need testing for coronavirus (COVID-19).

I am concerned about shortages for my CLL and other medications.
I am anxious about my own health during this pandemic

- Strongly agree: 29% Post, 42% Pre
- Agree: 12% Post, 44% Pre
- Neutral: 12% Post, 12% Pre
- Disagree: 2% Post, 1% Pre
- Strongly disagree: 1% Post, 1% Pre

In light of the pandemic, I plan to:

- Stay at home except for my “essential work” and shopping for necessities: 21% Post, 23% Pre
- Stay at home except for shopping for necessities: 26% Post, 31% Pre
- Stay at home and let my family or friends shop for me or have necessities delivered: 39% Post, 48% Pre
- I have taken extreme measures to shelter away from family with virtually no live social contact: 5% Post, 8% Pre
I understand the precautions that I should be taking as a CLL patient during the coronavirus (COVID-19) pandemic.

- Strongly agree: 70% (Post), 41% (Pre)
- Agree: 38% (Post), 25% (Pre)
- Neutral: 14% (Post), 14% (Pre)
- Disagree: 7% (Post), 0% (Pre)
- Strongly disagree: 1% (Post), 0% (Pre)

I understand what I should do if I need testing for coronavirus (COVID-19).

- Strongly agree: 52% (Post), 21% (Pre)
- Agree: 40% (Post), 38% (Pre)
- Neutral: 6% (Post), 21% (Pre)
- Disagree: 17% (Post), 1% (Pre)
- Strongly disagree: 4% (Post), 1% (Pre)
I am concerned about shortages for my CLL and other medications.

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<tr>
<th>Opinion</th>
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<td>Strongly agree</td>
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<td>Agree</td>
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<td>Strongly disagree</td>
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In light of the pandemic, I plan to:

1. Stay at home except for my “essential work” and shopping for necessities.
   - Pre: 17%
   - Post: 18%
2. Stay at home except for shopping for necessities.
   - Pre: 31%
   - Post: 31%
3. Stay at home and let my family or friends shop for me or have necessities delivered.
   - Pre: 44%
   - Post: 55%
4. I have taken extreme measures to shelter away from family with virtually no live social contact.
   - Pre: 7%
   - Post: 5%
The Future of CAR-T Therapy: Can CAR-T Cure CLL?

Webinar Outcomes Report

Date: November 17, 2020

Total # Registered: 733
Total # Attended: 457

CLL Society asked webinar participants 2 poll questions during the live session. The first question was posed to attendees both at the beginning and the end of the webinar to measure learning and changes in knowledge. At the end of the webinar, 98% of the audience reported confidence in their understanding of how CAR-T Therapy works as opposed to 45% in the beginning of the webinar. Only 2% of the audience had received CAR-T Therapy.

I am confident in my understanding of how CAR-T Therapy works

![Bar chart showing confidence levels pre and post webinar](chart.png)
Evaluation Data

Approximately 57% of attendees completed the evaluation (n=261).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, one was a patient’s advocate and associated with industry.
Please rate the webinar overall

- Excellent: 85%
- Good: 14%
- Average: 1%
- Fair/Needs Improvement: 0%
- Poor: 0%

After attending the webinar, I am more confident in my knowledge in this subject area

- Strongly Agree: 54%
- Agree: 42%
- Neutral: 3%
- Disagree: 1%
- Strongly Disagree: 1%
During registration, we asked people “How did you hear about this event?”. Of the respondents who selected “Another organization or avenue,” responses included from a spouse, online article, a friend with CLL, and support group members, among others.
Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of CLL Society’s CAR-T Webinar held 11/17/2020. They have been organized based on type of feedback. These statements were provided in response to the question, “Please include any additional comments about today’s webinar.”

Positive/Affirming

- It was awesome! Thank you so very much!!
- Really good and easy to understand! Very encouraging for us patients.
- Very informative and encouraging.
- Thank you!
- Great presenter and well done for non-medical folks.
- All very informative, especially the Q&A session.
- Excellent balance of presentation and questions. Speaker knowledgeable and yet related a complex subject in easy to understand terms.
- Fantastic, as usual.
- Very informative & slides assisting in a better understanding of CAR-T process.
- Excellent presentation and Q&A.
- Speaker is very knowledgeable and explained the subject very clearly and easy to understand. He did a great job.
• Every time I thought of a question, you answered it. Thank you.
• Clear and understandable presentation. Thank you.
• It was a basic, but informative seminar. I deeply appreciate the CLL Society, Dr. Koffman, and the presenter. Further, I'm hopeful for others, as well as myself, that this might actually be the equivalent of a 'magic bullet.' Bless you all!
• It was fantastic!!
• It was a great intro to Car T therapy. I have a greater understanding, which will help a great deal when looking into trials. Thank you!
• Great work Brian and Joe. Thank you.
• Outstanding presenter!
• Clear, comprehensive, understandable. Very useful.
• Excellent! I learned so much valuable information. The webinar was presented in a thorough and easily understood platform. Thank you!
• Outstanding! Maybe the best I have seen. Great speaker, great follow-up discussion with Dr. Koffman! Slides were excellent. Dr.Fraietta is such a good communicator, as is Dr. Koffman! Thank you for helping us understand this very promising new therapy!
• Excellent job!
• Many thanks to Dr Koffman for organizing this highly educating webinar. Dr. Fraietta is doing a wonderful job and given hope. There is a future with CLL... Thank you.
• Thank you for providing this webinar.
• Dr Fraietta is a fabulous presenter! He conveys complex concepts in ways patients can understand and he radiates enthusiasm and commitment to the future of CAR-T for CLL. Thank you for this webinar!
• Thank you again for a really great webinar!
• Well worth the time I took out to listen to this presentation. Well done.
• Thank you all! Great webinar!!!
• Dr. Fraietta did an outstanding job relaying new CAR-T research as well as explaining the basics of T-cell function. I hope more webinars on this topic will be presented early next year.

As in the past, the moderator and CLL Society staff were excellent in organizing the presentation and covering key questions from the audience. All of your past and ongoing efforts to educate CLL patients and others are greatly appreciated.

• The doctor was fantastic at explaining things and answering the questions. I'm so impressed, I wish I could request him for my 2nd opinion! I love that he explained things (as much as possible) on a level that patients can understand.
• Loved the way the presentation was delivered for novice listeners. He was great.
• Thank You.
• Great webinar! Thank you very much!
• Excellent webinar - both the speaker and the questions.
• So clearly explained. Great illustrations. Made this one of the best webinars I've attended.
• Dr. Joe Fraietta is a very good presenter. Very helpful in understanding the new technologies.
• Great Seminar.
• All of the CLL Society’s webinars have been educational and valuable for me personally. But this one was the best yet. I took six pages of notes, and each bullet was a new piece of information for me. Thank you!
• Another outstanding presentation. Thank you for it all.
• No specific comments, however, the quality of the CLL Society's webinars just keep getting better and better.
• Thank you for the great presentation!
• The presenter was an excellent speaker and instructor.
• The webinar was very informative and worthwhile. Based on the quality of this presentation, I want to continue to involve myself in the CLL Society. Thank you.
• This webinar was awesome. Learned a lot, Dr. Fraietta was great! Thanks for setting this up. It was invaluable.
• Great.
• I totally appreciate the effort to provide excellent research possibilities from dedicated doctors & researchers. It gives me hope my CLL will be total uMRD.
• Excellent speaker. He really explained CAR-T well.
• Thank you Brian and Patty for all you do. Best to you and your family.
• Great information. Good people. Good webinar.
• Very well presented and of great interest. Interested in further updates.
• The doctor’s presentation was very informative and presented in a way which was easily understood by the layman.
• The doctor who presented and the moderated were both excellent and educated us on a level which was understandable to the lay persons attending.
• Easily understood.
• Excellent presentation!
• I really appreciate all the time and effort you put into these programs. Everyone does an excellent job.
• The zoom webinar format is very easy to use, and I have had great luck staying tuned in! Thanks for your work.
• This was one of the best webinar (seminar) I have ever attended. Thank you.

Suggestions/Comments: Content

• Slides were very clear and helped with understanding the information.
• PowerPoint slides could be less cluttered.
• He spoke clearly and in a manner we could understand.
• Correct presentation level for this information.
• Initial polling question re knowledge about CAR-T should include a fifth choice, i.e., neutral.
• It was good but too much for a patient that just recently received a diagnosis and is in, and has been, on "watch and wait."
• This is a very small detail amidst a large cache of great information for which I am deeply appreciative. The first page put on the screen for discussion was entitled something like: ‘We are the enemy or the enemy is within us.’ From a psychological point of view, I think that this subtly transmits a negative message to patients. I am not my defective cells. The last thing I want to engage in is a war with myself. I am larger than my CLL and the sources of my strength and discernment are where I wish to put my focus. I hope you rename it.
• The doctor presenting the data seemed evasive in his answers.
• Is there a way to increase the volume of the audio on webcasts? I have the audio at max setting on my MacBook Pro and it is still low.
• The one thing that would be helpful to me is to enlarge the slides as some of the type is too small to read, especially when it is a split screen with the presenter on one side of the screen and slide on the other side.
• I really appreciate how they simplified the explanation of the process.
• Could have included quick survey of all CAR-T cell treatment approaches other than Kymirah like Yescarta. More details on possible side effects and probable percentage of occurrence.
• A very clear explanation of CAR-T and good slides to support.
• The presentation was a bit rushed.

Questions / Misc.

• I still don’t understand whether CAR-T cell therapy would be applicable to my CLL biomarker. If I am not allowed to have chemotherapy with unmutated CLL with chemo that seems to be part of the CAR-T cell therapy, then is CAR-T cell therapy an option for my type of CLL?
• Please ask Dr. MATO to express thoughts on this subject, in addition to your excellent guest speaker.
• I wish I could see other’s questions!
• Please let us know in newsletter so we can let others see the recording.
• You should provide contact info for the speaker - in this case, Dr Fraietta.
• I appreciate that this will be on the CLL Society website.
• Might be helpful to offer a weekly or monthly updated library with links to up-to-date research literature on CAR-T progress.
• Is there a chance that they will be doing CAR-T on patients that have never been treated? Or, at least have only been treated once? I am eager to see if it would work the same if one has fewer cancer cells?
• Please next time announce at the end how many participated in the webinar.
• We are in Australia so had to get up early. Been looking forward to it - couldn’t wait a few weeks for it to be available on CLL Society website. Though when it’s available, we will be watching again.
• Would appreciate more info on what is available in Canada.
• I just wanted to say I was late, so I will be re-watching next week. Had I been able to attend from the beginning I would have gotten more out of it. No treatment yet... 17p TP53 Zap70 Unmutated. I have much to learn for my upcoming fight.
• I am looking for a CAR-T trial and the information in the webinar was very useful.
• The CAR-T subject really interested me. Would like to know more about availability in the UK.
• My spouse has just started oral therapy for CLL. I just wanted to learn more about CAR-T therapy for future reference.
• The webinar provided me with the knowledge that at this time, I'm not ready for the CAR-T treatment.
• It was the most interesting of many CLL presentations I have viewed.
• Hoping for the next quantum leap in CAR-T for CLL.
• I suggest a future topic: sequencing various treatments. For example, what do we know about sequencing BTK inhibitors, PI3k inhibitors, venetoclax? Do any treatments preclude or suggest another subsequent treatment?
- Would be nice if they said in the alert email that the webinar is recorded. I was quite inconvenienced today having to ensure I was home at the time of the webinar and when it started, that's when I found out it was taped and I could have watched it later. Also, I think there should be some instructions for people so they know they have to download the Zoom app for tablets phones etc., which I discovered five minutes before the webinar (and I'm computer savvy - I actually build computers), but it said to just click on the link so I assumed that would work by itself.
- This is the first CLL webinar where I could understand everything that was discussed. I'm excited to check with my oncologist about CAR-T therapy at my next appointment.
- I'll talk to my doctor about trials, specifically CAR-T.
- I would have liked to know how many people were attending the webinar.

The CLL Society asked survey respondents to share topics of interest for future webinars. Included in the responses listed as “Other” were Treatments After Ibrutinib Stops Working, Richter’s Transformation, and 3rd Line Therapies, among others.
The CLL Society asked webinar participants 3 poll questions live during the session. The last two questions were posed to attendees both at the beginning and the end of the webinar to measure learning and changes in knowledge. At the end of the webinar, 94% of the audience reported more confidence in their understanding of what MRD testing measures as opposed to 48% in the beginning of the webinar. Similarly, at the beginning of the webinar, 52% reported confidence in their understanding about how MRD testing is being used in some CLL clinical trials and management, as opposed to 92% reporting confidence at the end of the session.
I am confident in my understanding of what MRD testing measures.

I am confident in my understanding of how and why MRD testing is being used in some CLL clinical trials and management.
Evaluation Data

Approximately 55% of attendees completed the evaluation (n=224).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, one was both a CLL advocate and patient, one was a Heme Sales Specialist, one preferred not to respond, and one was an advocate.
After attending the webinar, I am more confident in my knowledge in this subject area

- Strongly Agree: 71%
- Agree: 28%
- Neutral: 1%
- Disagree: 0%

I would recommend this webinar to another CLL patient

- Strongly Agree: 84%
- Agree: 15%
- Neutral: 1%
- Disagree: 0%
- Strongly Disagree: 0%
Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s MRD Webinar. They have been organized based on type of feedback. These statements were provided in response to the question, ‘Please include any additional comments about today's webinar.’
Positive/Affirming

- Thank you for educating me in MRD!
- My depth of understanding is way up!!!
- Dr. Mato was great. Clear, concise, understandable.
- Outstanding presentation as usual.
- Wonderful.
- Many thanks for a job well-done! I feel more empowered.
- Very informative!
- An excellent session. Lots of technical data made very accessible.
- Deeply useful. Thank you!
- Excellent, thank you.
- Very informative.
- Thank You!!!
- Excellent talk.
- Excellent.
- Dr. Mato is excellent in his presentations. He makes the information understandable.
- If it ran an extra half hour, the doctors could have spoken more slowly, and we would have had more time to absorb the content of the slides.
- Very interesting.
- GREAT! Heard about it through e-mail from CLL and then also on Facebook, I believe. Thanks!
- Excellent presentation and excellent questions. Very helpful in understanding the importance of UMRD.
- Dr. Mato is a very skilled communicator. Both his speaking style and slides were excellent and straightforward. Many other presenters could take lessons from Dr. Mato in how to do an effective presentation. Very well done!!
- Dr. Mato rocks.
- Very interesting. I learn more and more about CLL every time I watch these Webinars. Thank you so much for putting these on.
- This was so very timely and helpful to me in my CLL journey. Many thanks to CLL Society, Dr Kaufman, Dr Mato and Patty for making this possible!
- Thank you! My basic confusion about MRD has disappeared.
- This was a great webinar. I recently achieved MRD Negative Status but understand it is not a cure. Thank you for everyone's time in getting this together. Will this be available online to view at a later date?
- This was an outstanding program, very clearly presented and contained valuable information and insights. Thank you Drs. Koffman and Mato!!
- This was a fabulous webinar with extremely important new information. Dr. Mato was able to explain all of his slides very thoroughly and made the material covered very understandable. Thank you!
- Great meeting! I have better understanding of MRD. Thank you Dr Mato and Dr Koffman for your time and dedication to CLL.
- Dr. Mato did an excellent job of explaining MRD and the issues around it. His presentation was clear and contained points that are very relevant to CLL patients and not so technical as to be over their heads.
- Thanks. Useful info and intriguing that decision making might to some extent be based on remission status. Thanks for explaining ngs, for alerting me to how clinicians are thinking about MRD status in treating CLL.
Thank you--I'm MRD+ 6 months post Venetoclax/ibrutinib clinical trial for relapsed CLL following FCR. I never reached MRDneg status following FCR. I've been disheartened with this current status, but today's program makes it sound a bit more encouraging. I appreciate everyone’s time in making this program today possible.

Now I realize that being on imbruvica means never being in MRD. The truth is very disappointing!

Sincere appreciation Doctors for your valuable time and for sharing your professional knowledge on this particular topic.

Dr. Mato was SUPERB in the clarity of his presentation and the answers to Brian's WONDERFUL questions. Brian presented them beautifully, as usual.

We are ALL DEEPLY INDEBTED to Dr. Koffman for the CLL Society, for the EXCELLENT quality of EVERYTHING it does for patients and for the brilliant and BROAD SCALE information it provides. I am humbled by the caliber of human beings I have been so fortunate to be acquainted with and get to known Dr. Koffman and his wife Patty. May they live and be well for many decades. With great appreciation, Harvey Stern

Excellent presenter!

Thank you for squeezing in the last question about the initial clonality / 'bar code' test for clonoSEQ!

Heard Dr. Mato on other webinars and he is extremely good at making tough material understandable.

Many thanks, wonderful resource.

This was outstanding. I appreciate presentation of the scientific data and not making it too simplistic. Having the Q&A was very helpful and was well done.

I thought it was done very well. Thanks to Dr. Mato and the CLL society

Thank you very much!

I'm always doing more than 1 thing... especially with scientific medical jargon I should be listening completely...

Outstanding presentation and valuable information.

Excellent, thanks for the info.

Well done. There were questions answered that I never would have thought to ask. And I immediately asked my doctor. I am on ibrutinib, now for 3 years.

All my questions were answered. I'm very pleased with the speaker's knowledge. Thanks

I thought it was helpful. And we were given ample time to answer the questions, which was something I appreciated.

Learned so much!

Good mix of presentation and Q&A.

Dr Mata is a very good presenter. He made the subject matter easy to understand and gave the appropriate level of info for this group.

Very informative. I really like the presentation.

Dr Mato is our Doctor and he is amazing. It is so comforting to hear him talk about all of the exciting news about MRD. We both feel as though we learned so much from today's webinar. Thank you, Brian Koffman, for bringing so much knowledge to all of us. You run wonderful programs.

Thank you so much for the Zoom meetings on CLL they mean so much to a watch and wait patient.
• Excellent speaker and material. Dr. Kauffman made very efficient progress moderating the questions.
• Dr Mato was a great speaker, clear and to the point, kept on track with the topic.
• I sure do appreciate all the professionals in the CLL world that give so much of their time to help educate so many. Thank You all who made this production successful.
• The speaker was very clear and did not speak over the head of the audience
• Loved the information but especially the question and answer time.
• Both you and Mato were great. Such good questions and well thought out answers.
• Thanks so much for your tireless help and helpful information on CLL.
• Stay well.
• Great Webinar!! thanks for taking the time to help better educate us with MRD.
• Very informative; in addition to role of MRD I learned a few things I hadn't expected.
• I do appreciate this webinar very much. Dr. Mato succeeded in teaching me how MRD is an Oncologists decision making tool and not something for me to hang all my hopes or disappointments on. Thank you, both, Dr. Mato and Dr. Koffman!
• The information was not overly technical which I found beneficial in understanding MRD and its importance in CLL testing and longevity. I also felt the question/answer segment was very helpful. I will be having a MRD test in October after having been on Venetoclax since January 2019 (also had 6 Rituxan treatments from February through July 2019), so I feel better prepared to understand its significance in my CLL journey.
• Thanks for the great session.

Suggestions/Comments: Content

• I know this was recorded, and I hope I can find the recording on the CLL Society website, as I would like to watch it again.
• Wish there was a replay available.
• I lost the seminar a few times had to reboot itself.
• Just that the speed of discussion is fast, it is hard to absorb it.
• It may be a ZOOM problem, but I was unable to highlight and copy text on the screen which would then allow me to paste it into a text document for later review.
• I hope you post a recording - as Dr. Mato spoke rather quickly. I'd like to listen to his talk again.
• So much information in a short time period. Hard for me to keep up, but it reminds me that I have more studying to do.
• It would have been good to have the downloadable slides before the webinar start, so it is easier to follow or go back to concepts during the Q&A section.
• It was a LOT of information thrown at us very quickly. Dr. Mato was talking briskly, so while I was thinking about what he just said the rest was only partially heard by me. However, if there is recording of this webinar I can watch again as many times as I need, then I'm sure I would get a lot more out of it.
• More in depth talk on how to use this information relating to continuance of therapy with Venetoclax or whether to stop it once MRD reached.
• It was highly technical, and he went very fast. I’m sure it was great for health practitioners - but not a real stretch for your average patient. Maybe it's my age -- 72 -- but I have a master’s degree and worked in public health and I still found it difficult to follow with all the charts in the beginning. I think eventually he may want to have two separate presentations - one for researchers and practitioners, and a less data-laden one for patients. As a patient who is still in W&W and just likes to stay current, my main
take-homes were: 1) it's usually just another blood test; 2) you usually don't need it until you're in Tx or post-Tx; and most importantly 3) it is not generally used if you're on a BTK inhibitor like ibrutinib.; It is particularly relevant for Venetoclax patients. All of the charts in the beginning on efficacy were great but maybe too many – that's the type of info I expect my specialist to manage ... But THANK YOU as now I at least know what it is!! and that there's a reason I haven't had it yet

- A lot of the content presented was very technical and explained from a clinical perspective. It would be helpful as a patient to use more accessible terminology and practical/applicable considerations.
- It would be helpful to post Dr. Mato’s slides.
- Two recommendations: 1) Once your webinars are posted online, please provide links in the newsletter so folks can go back to the archive; and 2) I would have loved to have the slides. Was told you can't make them avail. Please reconsider.
- I asked a couple of questions that I thought were quite pertinent to the topic but was disappointed that the webinar never got around to these important issues.
- Questions on text from participating members.

Questions / Misc.

- How can I make sure that my oncologist is up-to-date on all this information?
- I like Brian's long hair, surfer look!
- Was still confused as to why they didn't think MRD status was relevant for patients on BTK inhibitors.
- Has any of the members had their blood samples sent in for the clonoSEQ sequence analysis? MDA is slow in getting this started there.
I am confident that I know what routine medical care and vaccinations I should receive as part of my early CLL care:

- **Strongly Agree**: 43%
- **Agree**: 45%
- **Neutral**: 25%
- **Disagree**: 26%
- **Strongly Disagree**: 7%

The percentages are shown pre and post intervention.
I am confident that I know what tests and work-up are appropriate as part of my early CLL care:
CLL Society Webinar Outcomes Report

Just Diagnosed

Date: April 28, 2020

Total # Registered 424
Total # Attended 275

The CLL Society asked webinar attendees the same two poll questions at the beginning and conclusion of the webinar to measure learning. Attendees reported increased knowledge about medical care, vaccinations, and tests after participating in the webinar.

I am confident that I know what routine medical care and vaccinations I should receive as part of my early CLL care:

I am confident that I know what tests and work-up are appropriate as part of my early CLL care:
Evaluation Data

Approximately 77% of attendees completed the evaluation (n=201).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, one wrote in Friend and the other wrote in Industry.
Attending the webinar, I am more confident in my knowledge in this subject area

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<th>Strongly Agree</th>
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<th>Neutral</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<td>0%</td>
<td>5%</td>
<td>50%</td>
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I would recommend this webinar to another CLL patient

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<tr>
<th>Strongly Agree</th>
<th>Agree</th>
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<th>Disagree</th>
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<tr>
<td>79%</td>
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Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s Webinar, held July 22, 2019 entitled “A Psychological Perspective: Dealing with the CLL Emotional Roller Coaster.” They have been organized based on type of feedback. Some responses have been broken up in order to be categorized appropriately. These statements were provided in response to the question, “Please include any additional comments about today’s webinar.”

Positive/Affirming

- Very helpful information. Thank you so much!
- thank you
- One of the most informative I've experienced. Thank you so very much.
- Very good. Honest and realistic but hopeful. Described limitations
- Thank you, I am newly diagnosed and extremely scared.
- Being new diagnosed, I had questions and you answered very clearly where we could understand. Thank you
- Great Webinar! Wish I could convince my doctor to do the IGHV test!
- Well done. Please do it again.
- Thank you for hosting this very important and informational webinar!
- Thank so much. I am going to dive into my labs to get a better understanding of my CLL.
- It was an excellent, informative presentation
- Great to hear a professional talk about the things that are a concern when living with CLL
- thanks for the newest research from the Mayo clinic on CLL. CLL specialists are vital to patients!
- Very helpful, educational lecture. Benefit me a lot. Most of the information I've never heard from my doctor.
- I really appreciate your work and these webinars.
- Information on MBL particularly interesting and the genetics of CLL
- I would have liked it to have gone on longer. I really liked the question and answer portion. That was extremely helpful.
- Thanks for all of your work in presenting these webinars and the valuable information on the website.
- Thought content was perfect and Dr. K spoke in laymen's terms. Very helpful.
- Thank you. Even though it was a bit technical I was able to follow the comments very well. I will go back to this webinar once it is posted and review the information.
- Excellent information. I really liked the questions asked after the doctor was finished. The doctor was really good about explaining things in layman terms.
- info was so good. fills in a lot of gaps for me.
Your guest Dr. Neil Kay was very informative, and he make it easy to understand his presentation on CLL. Thank you for having these webinars as they are so helpful. Please keep them coming!

Overall, the webinar was very informative. I found the information concerning the immunizations and additional cancer screenings particularly helpful. I have had CLL for a couple of years and have not been information of that. Thank you

I found the webinar to be very good and the power point charts to be very helpful.

Dr Kay presented technical clinical information in a way that non-clinicians could understand. Very informative.

Thank you for the information. It was interesting learning more about CLL and what to expect in the coming years.

Thank you! Knowledge really is powerful to the course of treatment and prognosis for the CLL patient.

Very informative

A good balance between technical terms and lay explanation of what the terms mean.

Even though I'm not newly diagnosed CLL patient, webinar very useful to know.

These Webinars by the CLL Society are a great service. I appreciate them.

Wonderful webinar with valuable information.

I think this 1 was the best for me. Great Job!

Great overview for this newly diagnosed and scared CLL patient.

Webinar speaker and content were excellent.

First webinar so very informative. Thank you

The webinar was very informative! I need to listen to it again and again to be able to retain all the beneficial information?! I was diagnosed with CLL in March 2020. Thank you so much for providing this wonderful CLL webinar!

I look forward to listening to the replay as this webinar was GREAT and I know I missed some good information.

Dr. Kay did a wonderful job! He originally diagnosed me at the Mayo in Rochester and is an amazing doctor! It was good to hear from him again.

thank you for the great information.

Thank You!

Thanks so much for this webinar and also for putting it on the website as I need to go back when I have questions. I am so thankful I found your website.

Thank you so much--this was extremely useful. Solidified some of what I knew, plenty of new information, and clarified some terminology as well. Really clear, useful, well-paced. Really appreciate it! Stay well!

Exceedingly grateful for the CLL Society and wonderful guest. I hope we will have many more webinars with Dr. Neil Kay. This feels like a new level of support. Newly diagnosed people could save much time and worry by watching it. I feel more knowledgeable, less alone and know what to focus on. Thank you so much! (My partner also listened in and I would like to send a link to the webinar to my hematologist).

I found it highly informative. Dr Kaye helped answer many of my questions.

This webinar was very helpful to me as I am just beginning my journey.

Very good and informative.

It helped me to understand the process a lot more than when I was trying to find information on the internet.

Thank you for your on-going excellent work. I am new to the CLL Society. I have benefited much from the knowledge I am gaining through this webinar as well as the COVID-19/CLL webinars I have joined. I don't feel so alone anymore. One million thanks to you all for this incredible service you are providing to the CLL community. God bless you!

The best new patient webinar I have watched.

The knowledge that Dr. Kay and Dr Koffman bring to us is very valuable and helps tremendously. Thanks

Dr. Neil Kay was very informative. Thank you, Dr. & Mrs. Koffman for arranging his webinar presentation.

Even though I was diagnosed 5 years ago, I still learned some new information. thought it was great. I am very thankful for Brian and his continued support of the CLL community. It's a great benefit to have access to this information. I have attended a few meetings now and I find them all to be beneficial. The medical staff is very credible and smart. Overall, I want to thank you for access to this information and helping us CLL patients.

The webinar was overall very informative.

Overall, there was great information shared.

Very informative, a lot of it was over my head but I still got a lot out of listening to it. Glad i can go now & review it online.
Thank you for all you do!

overall good webinar

I'm thankful that the webinar will be available on cllsociety.org so that I can watch again.

Suggestions: Content/Speakers

- Presentation was more technical than I anticipated. Will check back in on future lectures for info on dealing with CLL/SLL on a more personal level.
- I am hearing impaired. Closed Captioning or a transcript of the meeting would be helpful. Or, if it is possible to see the speaker so their lips can be read. Even a small picture-in-picture in the corner of the speaker would be wonderful. Thank you!
- I prefer to see the video of the participants, it helps 'connect' easier.
- Wish there was more time for additional questions.
- Unfortunately, for me it was a bit overwhelming to understand because of the plethora of technical terminology and some poor sound quality by the presenter.
- would be nice to stay longer on q & a -- maybe optional 15 minutes after for those who want to listen. Thank you.
- Dr. Kay referenced EGCG use and to reach out to him. I am interested. How do I get a hold of him?
- Minor frustration: too many TLAs. (three letter abbreviations). I suggest these are spelled out (at least once) on the slides.
- It would be nice to have a longer Q&A time. Maybe extend it 15 minutes for those who want to stay on. Thank you
- I found some of the 'medical dialogue' hard to follow when the doctor talked quickly.
- Was a little too quick on CLL specific terms/
- My ONLY suggestion is to make sure your guest speaker is consistently speaking into the microphone. There were times when his voice would trail off as if he was perhaps turning his head away from the microphone. That would be a good time to say we want to hear every word and gently remind him to stay focused on speaking directly into the microphone. Don't mean that as criticism but rather just as a respectful suggestion because we patients DO want to hear every word!
- A tad too technical for newcomers -MHO.
- very technical for us non-doctors.
- Would like to have seen him address more Rai Stage 2 and what to expect.
- I thought that maybe It was conducted at a little higher level as far as terminology than might be best for true 'newly diagnosed' patients. Must admit, I've 'been around' for a couple of years, so I was able to follow fairly well. But I feel for anyone who was really completely new to the disease and terminology.
- It would be nice to have more Q&A.
- It would be extremely helpful if we were provided with slides before start of webinar so that we could make notes on them while listening. Thank you.
- This was a webinar for other doctors.
- The ability to see the speakers would have improved the participants' experience. Also, Dr. Kay quickly got into medical jargon rather than introducing CLL in a manner that's easier to understand... particularly for those who've been recently diagnosed or are not yet in treatment.
- I am so very grateful that Dr. Kay made time in his incredibly limited schedule to give us this presentation. Unfortunately, the webinar was a bit rushed and not long enough - especially for those newly diagnosed who won't be familiar with much of the lingo. I was diagnosed 5 years ago and still found that it was a lot of information to digest quickly. Definitely not enough time for Q&A.
- Not a good idea to focus on survival rate. I do not want to countdown my months left. Please provide slides, so I can focus on the other information.
- Wish there was another 15 minutes for questions.
- Would have liked more time for questions.
- I would have liked to hear more layman-appropriate explanations of some of the terms used and more advice on living in Watch & Wait.
- Recommend larger font (double) for the charts. I plug the laptop into the TV. Perhaps make charts available - ahead of time? Viewers could down-load the charts and follow along on their PC.
- A lot of jargon. I'm a retired PE, was diagnosed in August 2018, and started a 3-drug Phase 3 in September 2019. So, I learned some facts, details, such as I am one of the 3/10 patients, and the fish-bone mapping can change. My spouse is a retired AP Bio teacher; she hung with the jargon - a lot better than I. (A few times, I would ask - 'Am I in that group?') Example: I am the non-mutated case. Perhaps consider - teaching a new 3/10 patient how to absorb what is ahead. Perhaps tier the jargon into tiers. Tier 1
would be those insights that should be absorbed, Tier 2 would be jargon to be logged -
as immerging need to know. Tier 3 is just that, Tier 3. The is and can be a very
complex affair. Newbies should take heart that CLL research is not a static state.
(Somewhat from point 3) CLL treatment is a rapidly expanding science. CLL patients
should be very optimistic.

- I like the format, it would be nice to see a face, but not a big deal.
- very technical. would have benefited more by more slowly walking through.
- Dr. Kay spoke a little too quickly for notetaking, plus some of the medical jargon was
  beyond me today.
- One area of feedback may be to make it slightly more relatable by speaking in common
terms rather than highly clinical medical terms. Some of it was harder to follow. Also,
  there are some great questions so more time for Q&A would be great.
- I felt the doctor explained everything very well.
- I appreciate the way Neil (and Brian) incorporate both the broadest concerns of those
  new to this path, while also providing details (like vaccine considerations) that will be
  remembered and used later. (And I need to check on my pneumonia vax at next
  opportunity!)
- Slow down a little. Lots of information to cover. Or maybe make the webinar 30 minutes
  longer or break it into part one and part two.
- I would like to hear more about how today’s CLL treatments are impacting overall
  survival rates.
- Easy to get lost in the terminology and abbreviations used. If there was a list of
  abbreviations and scientific vocabulary with definitions on each page--that would help a
  LOT.
- If it is possible next time could we view the speaker and see the slides alongside?
- It is was very helpful to me to learn about immunizations, genetic prognosticators and
  even green tea extract today. I am interested in obtaining and trying some of the green
  tea extract (EGCG), but I do not know how much to take nor how to buy the brand from
  Japan you mentioned. Could you direct me to a link or tell me how to get it and how
  much to take?
- I have difficulty hearing unless I can read lips or see closed captioning. Can either of
  those be provided?

Misc.

- I want more info on the best green tea extract. Where can I get it?
- None.
- Would like to know more about how to reach the Doctors.
- Lots of material. Is this available for rebroadcast?
- Packed with formation. I'll have to read the notes several times to absorb all the info.
- How can I get best green tea extract?
- audio a bit muffled at times.
- I have signed up for the Amazon site so the Society will receive a percentage based on
  my qualifying orders.
- I joined a few minutes late and missed opening remarks. I would welcome more info on
  risks for early stage CLL and covid-19 exposure and contracting the disease. Thank you!
- I hope this webinar will be available on your website.
- I look forward to listening again to understand better.
- The 'confident in my knowledge' is dependent on access to the slide presentation and Dr
  Kay's explanation! (Which I know you will provide.) It doesn't mean I am confident in my
  memory! :)
- It would help to be able to download the slides and take notes on them.
- Would like to reference again. Especially part about vaccines.
- I received my Bag It and I just love it. So very helpful!
- I will look for the slides so I can review again.
- I lost my laptop connection about 3/4 way through but dialed in and could listen to the
  ending questions.
- I've been forgetting all about my CLL with regards to Jargon. I get tested every 6
  months, but my numbers thank God haven't really changed since I was told I have it (5
  years ago). It was good to know that the testing every 6 months is a guideline which I'm
  doing. After seeing one point on the slide that mentioned you should be going to a
  clinic or doctor who specializes in CLL, I believe I'll start going back to Mayo Clinic
  instead of going to the local hematologist who interprets the numbers for me. (Usually
  it's a simple comment like 'your numbers look good'.)
- I would like to know the products for Green Tea extract that you can purchase over the
  counter. He said to email him, but I did not know where.
I learned my first oncologist pushed me into two unnecessary CAT scans. It has made me reluctant to accept a CAT scan recommendation for another condition I have. Needless to say, I'm angry!
CLL Society COVID-19 Virtual Community Meeting Outcomes Report

Date: June 18, 2020

Total # Registered 882
Total # Attended 605

The CLL Society asked virtual community meeting attendees 5 poll questions live during the session. The last four questions were posed to attendees both at the beginning and the end of the virtual community meeting to measure learning and changes in behavior and emotions. Attendees reported increased knowledge about the precautions they should be taking at the end of the virtual meeting. The percentage of the audience reporting that they were not yet changing their social distancing behavior increased at the end of the session.

Have you attended a CLL Society COVID-19 Virtual Community Meeting prior to this one?

- Yes: 64%
- No: 36%
I understand the precautions that I should be taking as a CLL patient during the coronavirus (COVID-19) pandemic.

The current pandemic: (choose all that apply)
What is your greatest fear?

- Getting Covid-19 and becoming critical ill because of having CLL: Pre 7%, Post 5%, Pre 75%, Post 76%
- Getting COVID-19 and being denied the best possible care because of having CLL and/or because of my age: Pre 1%, Post 0%
- Running out of medications: Pre 12%, Post 14%
- Long term social and economic disruption: Pre 4%, Post 5%
- How I can return to a "normal" life: Pre 12%, Post 14%

I am making the following changes as the public reopens:

- I am not yet changing my social distancing behavior: Pre 11%, Post 13%
- One or more of the above: Pre 5%, Post 12%
- Going back to work, if applicable: Pre 6%, Post 27%
- Increasing social activity outside the home, such as eating out or gathering in small groups: Pre 19%, Post 27%
- Increasing essential activity outside the home, such as shopping for food and medicine: Pre 43%, Post 58%

Post - Pre
Evaluation Data

Approximately 44% of attendees completed the evaluation (n=267).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, one was both a Caregiver and CLL Patient, one from the pharmaceutical industry, and one worked in research.

Which best describes your role with CLL?

- CLL Patient: 93%
- Caregiver: 4%
- Loved One of CLL Patient (but not the primary caregiver): 1%
- Healthcare Professional: 1%
- Other: 1%

Please rate the webinar overall.

- Excellent: 69%
- Good: 25%
- Average: 1%
- Fair/Needs Improvement: 1%
- Poor: 1%
Please see the responses for people who selected Other for the question, “What topics around COVID-19 are you most interested in?”

Re-entry

- Going back to work (symphony orchestra).
- The topic re-entry.
- Re-entry of extended family.
- While I felt that my beliefs and action about COVID-19 virus were reinforced, I would have liked more thoughts about getting out more and reengaging more with family and friends. How dangerous is giving someone a hug? Is it necessary to wear gloves when going into a store? Is frequent use of hand sanitizer enough?
- Returning to work in healthcare.
- As a CLL household that is living the pure isolation, I was hoping to hear definitions toward those actions we could begin taking.
- Housecleaning service into my home?
- Re-entering my career as a dental hygienist
- When to return to work.

Medical

- Is blood type a factor that influences risk of COVID-19?
- COVID-19 therapies and potential vaccine.
- As things open up our chances of being exposed to COVID-19 are increasing. What if we get it? What should we do in order to get the best possible care, particularly when we cannot rely on a patient advocate or caregiver to be present with us in the hospital?
- Vaccines.
Other

- What is confusing and tragic, CDC guidelines changed as the COVID-19 developed and proceeded March 1, to present. The pictures and news reports of New York, Washington, states and others had to change what was normal to protect staff and patients because of lack of sufficient PPE. For years, medical staff knew what to reach for to protect themselves and patients so disease or infections wouldn’t be transmitted to others. It’s common knowledge…masks, shields, gowns, gloves, were the basics and N95 masks for true infections. The medical world got down-graded…the disposable masks were considered safe, what when normally they would wear a N95 mask, gown up instead of trash bags in some situations. It leaves an average person saying why so many changes…because the supplies were short (or quite close to nothing) so substitutions were made. Many medical staff became ill or died because of lack of proper equipment…How can we trust the CDC with so many changes from one day to the other.???. We are left to use our judgement and do our best to keep family and cancer patients safe!!

Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s first COVID-19 Virtual Community Meeting. They have been organized based on type of feedback. These statements were provided in response to the question, “Please include any additional comments about today’s webinar.”

Positive/Affirming

- Overall, very good presentation
- Thank you. Much appreciated.
- Very informative. Grateful for CLL Foundation providing this forum.
- Excellent!
- Thanks so much for providing this webinar. It was very helpful.
- Excellent content, knowledgeable panelists. Thank you for an informative webinar!
- Thank you for providing this to us during this time of such uncertainty.
- Thank you to everyone and the Society for these sessions.
- Very informative and helpful. Thanks to all who are involved in putting together this and previous seminars.
- well done. thank you.
- Thank you for putting this forum together!
- Great info specific to the CLL community
- Thank you so much. Very helpful.
- Very helpful. Thank you!!
- Thank you for doing this
- These webinars have been immensely helpful to me in managing my risk and anxiety, and overall learning more about my fairly recent diagnosis. Thank you!
• I love Dr. Leclair. Direct, succinct, and practical.
• This was really great - thank you CLL Society. The docs did not overlap in their presentations. All great information. I look forward to an update on all of this in a few months when we have more data.
• Always informative and timely information.
• Excellent meeting with much useful, practical information.
• Extremely informative webinar. Made me really think about what I need to do to re-enter the social world.
• Excellent.
• I found the presentations and Q&A very informative. Overall, I found this very helpful and hopeful.
• Thank you so much. Look forward the next one.
• Well done!
• reassuring and informative.
• You all do a fantastic job educating us! Thank you!
• Great information from your panel and I look forward to the next meeting. Thank you CLL Society for all that you do!
• Great group of presenters. I appreciated the diverse group of physicians and their different perspectives.
• Dr. Leclair’s discussion about selecting the best labs to do testing was very helpful.
• Well done. Good info if somewhat repetitive.
• Very informative! Thank You. the staff and the speakers.
• Great speakers! So great to get CLL specific info!
• Best one yet!
• Most comprehensive and well-informed webinar that I have attended over the past 3 months related to COVID-19 - particularly for cancer patients. Well done and thank you to CLL Society + all of the panelists!
• Thank you ALL for a very informative webinar. The info helped clarify my concerns.
• Excellent --- thanks so much and looking forward to the next one.
• Very well thought out and organized presentation. Look forward to the next. Stay well!
• Very informative & helpful. Thank you.
• some great new info (e.g. selectivity of Roche Ab test) and some great common-sense confirmation of what I'd suspected: there isn't any magic, I'm not off the hook.
• A good meeting, but a bit redundant. Thank you for your work!
• Excellent panel!! Appreciate Dr. Koffman's summarization of questions and representation of us, the CLL community to the panelists!
• Excellent online user-friendly webinar format (questions, videos, speaker mechanics, etc.
• Very informative discussion with useful current information.
• Dr. Koffman has a very nice manner. He maintains control but allows the expert guests plenty of room to get across their points.
• Very informative! I am retired with a small job at an antique shop and made a choice last week to not go back to that job as I could not distance from people and it is not safe there. Glad I made that decision. Thank you so much for this webinar.
Appreciate the doctors who participated. Also appreciate these speakers giving their answers to questions in terms that were more understandable to the general person.

Excellent, I cannot say enough good about the meeting or speakers. Well organized and tons of information provided by participants. Everything discussed was relevant to our present-day situation and CLL.

Thank you for the valuable information! I am always second guessing my decisions regarding re-entry due to the inadequate government response to this pandemic. Your information has reassured me that I have been making the best decisions. I feel much more confident now in my ability to handle my health situation in the midst of this pandemic.

Many thanks to all the physicians’ kind enough to share their time and expertise and to Dr. Koffman for hosting. Well done!

As always, the webinar was excellent.

Thank you! Very helpful! *(I had to duck out early but will watch the end of the recorded session later.)*

Thank you for making CLL information available. So glad we have this organization and I will contribute.

Another excellent webinar presentation by CLL Society and the doctors who participated. Thank you again, Dr. Koffman & Patty Koffman, for all you do to make this happen. I have ‘attended’ all 4 webinars & found helpful information in each of them.

Please thank the panel for helping...

The panelists were all very knowledgeable and gave helpful information in a manner that was readily understandable. Thank you Dr. Koffman for your endeavors/

I like when some of the doctors make some clear differentiations between the different CLL types of patients (i.e., Watch & Wait vs those on advanced therapies) and how the world of COVID-19 applies differently to each of the sub-groups of CLL patients

I enjoyed hearing from a wide range of specialists. Excellent faculty. Much appreciated!

Excellent seminar, thank you so much. All the physicians are just exceptional.

I particularly liked that you included the recommendations for various situations. I read the .gov email and anther by one of our senators, but sometimes it can be confusing.

Excellent program. Reinforced what we knew already, but very good.

Thank you again for these webinars and all you do.

This was an excellent presentation!

Thanks, appreciate the opportunity to learn!

Thanks -- looking forward to seeing what you come up with next!

Excellent! Much appreciated.

Susan Leclair’s information was very helpful to me. The other panelists shared excellent information as well. Their experience is daunting and valuable to me.

As a patient in the U.K. I found the meeting interesting and felt guidance to those with CLL in the US and the UK is following broadly similar lines.

I appreciated especially the discussion/explanations of the virus’s behavior and, as always, Dr. Leclair’s comments about testing. I feel I came away having a better understanding.

Thanks for keeping us informed--the first step to staying safe.

The doctors were all a very well-spoken group with their topics, went quickly, I was about 10 mins. late. Felt they meshed together well and covered a lot of information...some a
little too fast to write things down. I see where we can go to review again. I like the live meetings better than voice only. Nicely done!! Thank you to all that participated. Really nice doctors. (I’m from rural coastal Maine.)

• As things reopen, it is important for us to understand how we can renter safely. This virtual meeting helped.
• Thanks. As usual it had very useful information.
  I am so grateful for these webinars and the newsletter the CLL Society sends out
• I found it very helpful and wish to pass on my thanks to everyone involved. First time I joined one of your Webinars live and seen your other Webinars as videos. Live in the UK, and it is good to get a wider perspective on issues relating to COVID-19 and CLL.
• Thank you. Good discussions.
• I am glad to learn more about how to take good care of myself during this epidemic. I have gone in to take lab tests for my doctors and then discussed results in a video appointment. This is helpful. I learned a lot from the webinar. Got good facts and advice from the well-informed doctors.
• Looking forward to the next one!
• I always come away from these sessions with new information that really helps to manage my CLL, and, now, with the pandemic, to best avoid catching the virus. Thanks so much for all you do to help those of us who are dealing with CLL.
• Very informative and helpful. terrific panel of knowledgeable professionals.
  thank you for assembling this webinar.
• Good seminar. Especially liked the part about antibody testing.

Suggestions/Comments: Content & Speakers

• Saw questions I was hoping to have answered, but good questions, no answers.
• Being from England it interesting to see the differences/similarities between America and us here about dealing with CLL. I would have liked to have gotten into the research and some data on likely good and those that have CLL then got COVID-19.
• Prepared comments ran long, although they were helpful. Next time look for ways to condense prepared items and respond to most common questions.
• While all of the speakers were excellent it might give us more time for Q&A if the number of speakers was smaller.
• Wish there was additional time for answering the questions.
• Well done, however many questions unanswered. Perhaps a webinar for just Q&A alone would be productive.
• I hope future seminars will consider medical options for CLL. Thanks.
• Communication and reinforcement of beneficial behaviors.
• More time needed to answer survey questions - especially for the ones at the end.
• I was hoping there would be more about re-entering society. Dr. Hanson was given a few questions regarding haircuts and etc., but I was really hoping there would be more real-world issues like that answered. Regardless, thanks for providing these webinars!
• If possible, when a drug is up on a slide that only shows the chemical (generic) name, would you please list the brand name and manufacturer if possible? That is easier to remember and investigate.
- I need more information on determining personal level of immunity through CBC Diff results.
- Way too much time was spent on very repetitive talks. We all long ago learned that social distancing and hand washing are important. We did not need four different speakers to tell us that. Maybe you could select one speaker to set the stage with a 5-7-minute talk focused on the topic of the day. Other speakers should be limited to a short add-on to the main talk. Overall, by 20 past the hour, the webinar should be moving to questions.
- More practical info, i.e., routine health care, shopping, visits with relatives and friends, how do you determine the safety of hair, nail care, etc.
- Had sound and video dropouts more so for this presentation. Dr Susan Leclair's detailed slides were a helpful workaround. If somebody could type the Q&A that could help. Also perhaps type a summary transcript. It was still well worth attending. Many thanks for all your efforts.
- Why is it I never read anyone mention using disposable gloves when going to supermarket, or anywhere public where we may have to touch things?
- Still would like more detailed info regarding the drugs (not vaccines). I am interested in dexamethasone. Speaker started by saying does not know much about it but is not hopeful anyway. Also, Mayo is starting trials for 1st responders with hydrochloroquine and finally ibrutinib as possible treatment for those not on it. Is there someone who follows this at labs and patient data, especially hospitals. I might be asking the impossible, but it would be great to stay tuned through development. It is all high-risk patients can cling onto right now as COVID-19 numbers are going up.
- Need a few more seconds to finish survey at beginning and end. Perhaps there needs to be a webinar topic of 'Re-entry Baby Steps.' I suspect we are giving into both science and fears. The Baby Steps webinar could articulate more specifics 'do's' - such as okay to get take-out food. What about walking in the neighborhood or a local part - free of fears regarding getting within 25 feet of other humans! Another topic, how to choreograph a visit to your kids and grandkids.
- As an aside, our son graduated from the US Naval Academy. Part of Plebe Summer, Plebe Year - is rolled into the following statement, 'At the USNA they take away your unalienable rights - and give them back to you in the form of treats'. I am coming up on my 2nd year anniversary of CLL diagnosis. Another webinar topic - might be 'Your new CLL life.' Today's webinar gave insights toward realization that I will have an impaired immune system for the rest of my life. (I ask myself, what does that mean; not just in the era of COVID-19, but even in a COVID-19 free environment).
- Dr. Koffman: Perhaps you - and a few other CLL veterans could give us newbies into details regarding your ventures into the neighborhood, you expanded family, your friends.
- For future meetings: (A) Stages of CLL diagnosis and COVID-19 is important; (B) Mitigation – Can diet/exercise/daily activities...influence Immune system in a positive way and how?; (C) Hope – What is in the works for treatments and the expected timing?
- Would like to hear from CLL patients themselves how they are handling re-entering during the summer.
- I would appreciate less time devoted to lectures – most (though not all) information was freely available in mainstream and scientific press -- and more to Q&A.
The Q & A's always get put off until the end. Why not make the whole webinar Q & A's?

Most of what the doctors shared was old news and frankly, uninteresting.

Although the speakers were knowledgeable, they did not add information on the topic of how to manage re-entry, except the obvious and not to re-entry because we are very high-risk.

As acknowledged during the meeting, too much time was spent on the presentations, which took away from the Q&A.

Your webinars are wonderful, but this one spent only a few minutes at the very end actually talking about the topic, Managing Re-entry. I still have all the questions I was wondering about. The webinars with fewer panelists seem to be more informative (but never let go of Susan!). Regarding the dexamethasone study from Oxford involving almost 6,500 people, although the paper has not been published yet, I don't think it was responsible for the doctor on the panel to outright dismiss the findings without first-hand knowledge of the study (especially given the sample size and location of the research). Another arm of the same study determined that hydroxychloroquine was ineffective, a conclusion that has been accepted. Sure, wait for the paper to be published, but I see no reason to doubt the veracity of these researchers just because steroids have not worked for viruses in the past. COVID-19 is an illness that will require many types of treatments for people presenting very different symptoms. Doctors will need many options, and at this point in the course of the disease anything that is shown to help some people should be available for doctors to try. What really worries me is that I have a very smart, progressive primary doc (who looks after my untreated CLL much better than my local hematologist does), but if I have to be hospitalized she will have no authority to direct my treatment. She can make suggestions to the hospital doc, but ultimately treatment decisions will be out of her hands. All the more reason to try to stay out of the hospital. Fortunately, where I live the numbers of cases are back down to where they were in early March. But as life opens up slowly, I want to know what is considered low risk behavior inside one's home when living with others who -- although they are very careful outside -- are not staying at home as I am

I suggest you dispense with the slides (many of which said the same thing) or offer them as a follow-up. Then throw the questions you get up on the screen and get the panelists to answer them. You will cover a lot more ground. I found this event well-intentioned but kind of boring, and I learned very little that was new. Really digging down into what people want to know--beyond what we already DO know--is where you can make a difference. Also, if you have access to these great doctors, how about a little education on the possible treatments, vaccines coming along--something we can’t read ourselves? (For a presentation like that, slides might be useful, but I strongly encourage you to use the technique where you click on each item as you get to it, without putting up the whole document--people end up reading the whole thing, losing track of what speaker is saying, and then being bored!).

I didn’t find the lengthy section on testing very useful and felt it was a bit technical in content.

I felt let down as it was supposed to be about managing re-entry, but I felt it never touched this topic.

Most of what was talked about has already been addressed numerous times by the press, so I did not learn anything new from this community meeting.

More question time from patients would be great.
It would have been helpful if the presentation slides were available before the Webinar, so I could concentrate on what speakers were saying and just add additional points to them where I needed to. I realize that this can be difficult to arrange when everyone concerned has a lot to do. I tried making notes but was unable to keep up with everything that was on the slides.

Questions / Misc.

- Will the questions asked and not answered be able to be answered and provided to attendees in written form after the seminar?
- My submitted question on having my housecleaner into my home was not answered. This was my main question, so I'm very disappointed. All of us have homes to clean!
- I really wanted my question on teeth cleaning answered, and I would have loved more practical questions being addressed. You have done a great job of educating us in general, but now I want some specific answers. Unfortunately, I am at Kaiser for CLL treatment. I love Kaiser and have gotten great treatment since 1989. But they don't have a CLL specialist in San Francisco. The hematologist is off on some project, so my assigned person is a NP who knows nothing about CLL. I will try to get my answer from them.
- Our question about antibody testing was not addressed. We believe we had COVID-19 in late Jan early Feb should we be tested for antibodies?
- Feel like I should space appts out a bit. Want to visit family in another state. Debating whether to drive or take train. (It is only 3 hours away, but difference in price is a lot.) How worried should I be staying at my brothers for a few days?
- What about the idea of extending your bubble of people to regularly interact with? I am still feeling a bit phobic about getting out beyond going for long walks, to the grocery store and drug store. Am about to make hair appts for next week because I feel that it is one of things I most want to do. Will try to get an early in the day appt. as it feels like the air quality will be better. Is that sensible? Does time of day matter. Am going to make dentist appt., an appt with dermatologist. Already have an appt with my oncologist for first week in July.
- I had asked a question that didn't get answered: As a Naprapath I need to know when do body aches and pains become a symptom of COVID-19. I am not working right now because of COVID-19 but wondering when it opens up.
- Is there a way of re-playing as I had a stay at home choir meeting competing for the timeslot?
- Kept going off and buffering.
- Unfortunately, timing-wise, it ran in partial conflict with an LLSC C-19 webinar.
- I didn't have enough time to answer all the questions in the first survey. Probably me...
CLL Society COVID-19 Virtual Community Meeting Outcomes Report
Date: April 17, 2020

Total # Registered 615
Total # Attended 437

Evaluation Data
Approximately 24% of attendees completed the evaluation (n=149).
Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, three were from the pharmaceutical industry, two were patients, one was a scientist, and the last person wrote nonprofit.
Please rate the overall webinar.

- Excellent: 73%
- Good: 25%
- Average: 1%
- Fair/Needs Improvement: 1%
- Poor: 0%

What topics around COVID-19 in future community meetings would you like us to include?

- Testing: 20%
- Staying protected: 15%
- Managing routine clinic visits: 10%
- Access to drugs: 10%
- Managing health emergencies: 15%
- Stages of CLL and COVID-19: 20%
- Expectations of caregivers and household members: 0%
- Other: 0%
Please see the responses for people who selected Other for the question, “What topics around COVID-19 in future community meetings would you want us to include?”

Medical questions:
- What is the best long-term hope for CLL patients to be protected from COVID-19, for those of us with relatively few functional B cells? Herd immunity? Convalescent plasma?
- Continue updating clinical trials info as it becomes available
- I would like to know about the role of local hematologists if an untreated CLL patient gets COVID. Would they be more knowledgeable about symptoms or treatment than a primary care doc? What should their role be if someone is hospitalized?

Medicine:
- Emerging COVID-19 treatments

Other:
- Most answers were we don't know which unfortunately is the case. Didn't get much real info from it. but thank you for trying anyway. i hope we'll know more later
- Perhaps if the answers to the questions could be a little shorter you would be able to cover more queries.
- Why is (academic) nursing's voice absent? Check out Betty Farrell at City of Hope. She's expert at symptom management.
- Managing insurance and Medicare
- Can I visit my partner who has stayed at home in his house for 3 weeks and is OK?

Verbatim Feedback
All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s first COVID-19 Virtual Community Meeting. They have been organized based on type of feedback. These statements were provided in response to the question, “Please include any additional comments about today's webinar.”

Positive/Affirming
- Thank you for these virtual meetings.
- Thank you very much. These webinars are so helpful!
- Very helpful! I think we really need this one, which was nothing but dealing with our questions! Thank you so much!
- Thank you. I feel so much support from you all. I heard things I needed to hear!!!!
- Thank you.
- Thank you for doing these community meetings. Very helpful during this time.
- Well done as always. Knowledge breeds confidence. Thank you.
- Thanks to Brian and all of the panelists for their time and expertise to keep us informed. I really appreciate the good information that is being shared so generously.
- Well organized. Impressed with the beginning survey questions and results posted so quickly. Hope to see more of these in the future. Appreciate all the doctors and their time.
Thank you for asking the tough questions.
Great appreciation for the effort put into this session by all involved!
These Community Meetings are great and help reduce my anxiety. I really appreciate everyone who participates and shares their knowledge. Thank you!
Thanks to you all for doing these webinars! I really have a hard time deciding my risk level in terms of whether I am in the 'vulnerable' population per the new federal phased guidelines. I am untreated but have a ALC that has doubled three times in three years so it is on the move but I am otherwise very healthy. Had pneumonia last fall for first time in my life but haven't been sick since, and rarely sick before that. Anyway... still hunting for an answer!
Please keep Susan LeClair on the panel! Everyone is invaluable and I thank CLL society for being! Accolades!
Thank you again, Dr. & Mrs. Koffman, for making this possible. We thank God for you. We learn so much every time we tune in. Ted & Mary Kay Bowersox, SJC, CA
First time attendee at CLL Society event. Really appreciate hearing from doctors. You hit all of the topics that are so concerning right now. Thanks, H
I can't thank you all enough for these valuable sessions!
Fantastic! Thank you so much for all that you give!
Thank you and your panel. The three additional doctors were helpful with their additional insight.
Thank you Brian, Patty and company for being incredibly caring, competent and generous with your superb devotion to and support of the CLL community!! Harvey Stern
In the absence of virtually any definitive data around Covid-19, I appreciated having the panel answer 'difficult,' speculative questions from the gut. Dr. Leclair's counsel is invaluable. We are in control, should be highly selective in our sources for information. The only sure way to not get Covid is to not get Covid. Suggestions -- a 'one-pager' -- as to how to reinforce and routinize our personal 'best practices' might be helpful to some CLL patients.
Thanks to each of the participants for the gift of your time.
Dr. Koffman and his panel engaged us at the appropriate level of sophistication. Dr. Koffman does a fantastic job of keeping things moving smartly and the medical experts are providing information treating the audience as responsible adults. The range of topics addressed were well-chosen. Thank you very much!
Thank you so much for doing this! Again: great job, and I appreciated it very much!
Enjoyed meeting. Informative but sobering than the doctors and scientists really are treading on 'new terrain' here and don't know a lot about COVID-19, in terms of data. The prospective malaria drug that is being touted has not been proven, except anecdotally. It's all very much unknown at present. We were informed it takes time to run tests and do studies to find a cure -- a working vaccine -- and we just are not there at this time. It was discouraging to hear the truth about this, but I'd rather hear the truth (even if it's not rosy) than hear the other. not based in reality.
Thanks. Excellent meeting. Dr. Hill was particularly helpful. Sorry I had to check out a few minutes before the conclusion.
I really appreciate the CLL Society and these informational webinars. You provide a wealth of valid information amid a sea of self-serving nonsense out there.
Really appreciated having an infectious disease specialist in the mix!
These virtual meetings have been very beneficial to me and my family.
• Good questions, good responses. I felt like I was getting expert advice from several CLL experts all together! Thank you! Stay safe, stay well...and don't get old.?
• This was the best yet! So clear and easy to follow! Thank you!
• I think the program was excellent and the moderator did a great job. It was my first time on this webinar but not my last CLL diagnosis May 2015 6mos chemo in remission.
• Very helpful. Thank you.
• We learned so much - the panel was fabulous and we (CLL patient and caregiver wife) hope you will do more. Thank you for putting so many brilliant people together for all of us to learn from. Kuddos. We plan to get active in the CLL Society when this pandemic is over.
• Thank you well done.
• Thank you so much for providing expert information and compassionate encouragement!
• Thank you!
• I think the presenters were extremely informative and I was able to grasp a better understanding of how to proceed in these uncertain times with my CLL. Thank you for reaching out to the CLL community. I know how much I appreciate the knowledge and support.
• Thank you so much for these meetings. Nowhere else could we get such valuable info from such distinguished presenters.
• Excellent presentation. Thank you!
• It was very helpful and informative and I felt much better about managing my health in this pandemic. Thank you!
• Very very good. Good topics. Well organized and good pacing. Minor tech issues with Dr. Hill's connection.
• Thanks!
• Thank you CLL Society! Another informative Virtual Community Meeting! Keep them coming!
• Thank you so very much for these meetings. I find them extremely informative!! Much appreciated.
• It was wonderful. Thank you for organizing these!

Suggestions: Content & Speakers

• I realize it's probably not possible but I would GREATLY APPRECIATE captions! I am hard of hearing and missed much of what was said. If there will be a transcript, please let me know. Thanks! Jill Goetz
• Wasn't sure how to get questions submitted
• Please provide us with a bit more time (30 seconds?) to fill in the start and end online surveys
• One highly verbal presenter talks way too much for too long and talks down to us as if we were in high school or completely new to the topic.
• It might be nice to hear from any patients who have already been infected with COVID-19. I know of one such person in the news: https://kartemquin.com/news/update-on-gordon-quinn%E2%80%99s-health
He is an acquaintance of my brother, who is also a Chicago filmmaker. I could try to contact Gordon on behalf of the Society.
• I wonder about the difference in patients at different stages of the disease. I am relatively new to this and without treatment. It is not really clear to me how all of this applies
differently to different stages of the disease, if at all (Susan mentioned something in this vein in the first session, and I felt that others on the panel disagreed with her). I understand the general principle of being immunocompromised etc., but curious about that stage difference. Also, please allow more time for the surveys, I am not able to complete them in the allotted time. One way to deal with it perhaps may be to post them earlier, say 15 minutes before the end of the session (or after the beginning), so there's enough time and we don't have to rush in answering the questions.

- One of the doctors had a heavy accent and would it be possible in that case to provide a closed caption in the event a participant has a heavy accent?
- I only wish it could have been longer and covered more questions. Thank you.
- Geri Gallagher (spouse of CLL patient)
- Some of the speakers took a long time to simply say: ‘We don’t know. We don’t have the data yet.’
- There was something I didn’t understand about what they were talking about the cytokines response. Could they cover this cytokines response on the next talk? Thank you. Anna
- I had to leave a few times because i was working but i saw a decent amount of it. it was great to see weirda and other experts i just wish they knew more real info they could tell us other than we don’t really know but that’s the way it is. its very scary time.
- Does it make sense to segregate the webast time/agenda to those in treatment vs. W&W? I just found some portions of the webcast relevant and other portions not relevant to me.
- I would love a webinar that just focused on COVID-19 and testing/treatments/vaccines in more detail. Appreciate all your efforts to keep us informed.
- Very interesting survey question: Greatest fear, with 69% selecting COVID-19 infection with clinical deterioration, rising to 79% after the seminar! Unfortunately, this question was not really addressed. No other question yielded such lopsided responses. What should a CLL patient due if hospitalized and getting close to needing a ventilator? Measure IL-6 level? Tocilizumab? Please, next time!
- The survey at beginning and end go too fast for me to have time to respond. I have attended all three Community Meetings, and I have not yet been able to finish a single survey.
- As caregiver for my husband, I am very concerned about when restrictions are lifted and my daughter and I return to work/school. How can we keep him safe?
- There were a few times when I thought to myself, ‘Yes, but how do I get to the point where I can do (or ask for) what you are suggesting?’ These wonderful experts who spend all their time with these diseases sometimes assume too much on the part of the patient. I would appreciate something about what to do when you have no caregiver, but live on your own away from family (because this is where I can afford to live).

Misc

- I got knocked out of the meeting after the first question until 1/2 way got back on secondary to a cable repair truck in the area. Is there a way that I can listen to this and the first 2 meetings again? Thanks
- Unfortunately zoom feed kept dropping throughout the session
- As caregiver for my husband, I am very concerned about when restrictions are lifted and my daughter and I return to work/school. How can we keep him safe?
CLL Society COVID-19 Virtual Community Meeting Outcomes Report

Date: April 3, 2020

Total # Registered  751
Total # Attended  566

Evaluation Data

Approximately 38% of attendees completed the evaluation (n=216).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, four were from the pharmaceutical industry, one was a physician, and one was an advocate.
Please rate the overall webinar.

- Excellent: 75%
- Good: 22%
- Other: 2%
- Fair/Needs Improvement: 0.5%
- Poor: 0.5%

What topics around COVID-19 in future community meetings would you like us to include?

- Testing
- Staying protected
- Managing routine clinic visits
- Access to drugs
- Managing health emergencies
- Stages of CLL and COVID-19
- Expecations of caregivers and household men
- Other
Please see the responses for people who selected Other for the question, “What topics around COVID-19 in future community meetings would you want us to include?”

Medical questions:
- Status of Covid-19 treatments and vaccine
- Any interesting data about people with CLL and Corona virus
- Ways to build up immune system to keep healthy
- Should CLL patients hospitalized with COVID-19 demand IVIG as Dr. Byrd of Ohio State has suggested?
- Any experience or data on CLL patients with COVID-19?
- Have they heard or treated CLL patients with COVID-19? And if so, what did they treat with? What are their thoughts of the inexpensive malaria drug with an antibiotic?
- A discussion on how the virus RNA infects and mRNA-1273 (how it works and the clinical trial).
- Potential treatments for COVID-19.
- How to do “telemedicine for basic health or CLL care, when patient is not tech savvy, &amp; or does not have proper equipment--ex: older patients.
- Any unusual/relevant international data you may acquire within the next few weeks.

Other:
- How to clean.
- Practical resources on how to find supplies online. (I see a lot of "only available in store; not subject for delivery or curbside pickup" at major retailers especially for cleaning supplies.)
- Guidance on foods and vitamins/supplements that may help keep us safe.
- Industry.
- Move on.

Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s first COVID-19 Virtual Community Meeting. They have been organized based on type of feedback. These statements were provided in response to the question, “Please include any additional comments about today’s webinar.”

Positive/Affirming
- Well done! Thank you.
- Well done Brian! My wife and I got the most use info from Dr. Leclaire and Tom Henry.
- Very well done! Excellent panel
- Very well done
- very nice job, q &amp; A was very good...doctors presented useful information
- Very informative and gave me peace of mind. So grateful to Dr Koffman for having these meetings
- Very good.
- Thought it was well done. Really appreciated you reserving most of the call for questions &amp; also not repeating mist of the material presented during the first call.
- This was my first time on the forum and I found it most helpful and reassuring and will be joining on the 17th April. I am from Aberdeen Scotland and our health system do differ
from USA as our NHS is available to everyone and we do not have medical insurance. Thank you for giving up your time.

- The panelists were excellent - many thanks to them for taking time out of their day. Also, many thanks to Dr & Patricia Koffman for their time and efforts in putting this together. These webinars speak directly to what is happening and the impact it has on me (a CLL patient) - kind of a 'where the rubber meets the road' basics and at a level that I can comprehend. Many thanks to all!!!
- The meeting was very good and reinforced a lot of what was said at the first meeting. I enjoyed it and found it to be helpful. I am most a bit bewildered about the extent to which we must go to process delivered food and items from store. I pretty much know, but am still processing all of these new measures, and particularly as they apply to CLL patients, as we are more vulnerable than the general population in addition to myself being well into senior years and having A-positive blood type. I believe the meeting was definitely helpful to reorient one to the new reality we are facing at this time.
- The information about antibodies in regards to COVID-19 testing was excellent. Also, I am grateful you mentioned IVIG (and subcutaneous). Dr. Koffman, you and your wife are amazing, I thank God for you and your dedication to helping us all.
- Thank you for providing these sessions. Much appreciated!!
- Thank you for doing this!
- Thank you for an excellent and informative session. There’s so much to know and understand, and this discussion filled gaps for me.
- Thank you for a very informative webinar. I will continue to practice self distancing and immaculate hand hygiene. I look forward to listening in again on 4/17.
- Thanks much to the smart, eloquent panel/
- Thanks for the info. It’s nice to hear from people I trust.....
- Thanks again for a great meeting.
- thanks
- Thank you!!
- Thank you!
- Thank you very much to all the panelists. This meeting was very informative.
- Thank you to Brian for putting these together.
- Thank you so much!
- Thank you so much for providing this information with such noted experts. I would not be able to get this locally. It is so helpful for both me, the patient, and my husband.
- Thank you for this conference and all of your great suggestions and we will continue to practice our stay at home routines till this virus passes. Stay well, Stay safe.
- Thank you for these wonderful meetings.
- Thank you for these webinars. I have learned something new both times and they make me feel cared about.
- Once again this was a very informative meeting. Thanks for putting this together.
- Nice job everyone!
- Loved it and the great professionals who gave their time. I have often wished CLL Society had a chatroom for CLL'ers but I would be thrilled to join a CLL Society virtual support group as there is no CLL support group in my neck of the woods in the Boonies north of Pittsburgh, PA. You’ve proven the superior ability of CLL Society to go virtual! Thanks!
- Looking forward to the next session. Got a lot out of today. Will likely have more questions by then.
- It was so informative. Thanks for gathering the experts and hosting this for us!
I really enjoyed it! Thanks you so much!
I appreciate this forum and information. Keep up the great work.
Good meeting! Looking forward to all we will know about COVID in two weeks time at the next meeting.
Hope it will be available online later as well.
Great, included lots of topics.
excellent. thank you.
Excellent information. Dr. LeClair does a great job of helping me understand COVID-19 testing. Good to hear that most medications should be available. Always good to hear from Dr. Mato and Dr. Brander regarding how to manage CLL during this pandemic.
Appreciated Dr. Koffman's funneling of questions he is getting from CLL community to the Drs. Especially appreciated Dr. Leclair, Dr. Mato, & Thomas Henry's preciseness & clarity.
Another excellent presentation, thank you. So appreciate Dr. & Mrs. Koffman 'Rounding up' all these expert practitioners! Your dedication to the CLL Community's welfare is such a blessing. You are our heroes!
All presenters are excellent. I feel so lucky to have this resource.
All of the participants did an outstanding job at relaying this sometimes complex and quickly emerging information. Please let them know that we greatly value the time and effort they devoted to this webinar. I look forward to the next one- please continue these webinars. Nice job - all of you.

*Thank you* to all of the the panel for being so generous with their time.
I find these webinars empowering, sharing your knowledge helps me so much. Thank-you.

**Suggestions: Content & Speakers**

• You beat covid 19 to death today. Time to move along to other news. You said another webinar in 2 weeks. We'll see what's up in 2 weeks, touch on covid and head to China for news.
• We are most interested in new material and information.
• is there anything a cll person can take to boost their immunity to offset this virus..would be a good question to discuss
• More time for the surveys would be appreciated. Maybe 10 more seconds. I've only been able to finish the survey once (out of 4 times) then noticed too late that there is a submit button as well. Thank you.
• Tried to answer survey questions, but survey ended before i could answer all questions both times .. maybe a little more time?
• Too much time with the pharmacist. Otherwise very nice.
• There was too much repetition from previous week. Repeating the same topics should be minimized.
• The question regarding the use of masks, whether they could be used more than once or sanitized wAs not fully answered. Would appreciate receiving a list of resources where we could find more answers would be appreciated.
• FYI:
  1) Please mention that COVID-19 related pneumonia differs from Bacterial Pneumonia. Only the discerning radiologist can tell the difference on a lung CT scan.
  2) My mother, a CLL patient who had post-op pneumonia in hospital, was denied IVIG
by her hospital for financial reasons, even though we demanded IVIG for and her CLL specialist recommended or prescribed IVIG for her. Sadly, she died soon afterwards...

- The current best drug practices and a little history over the last three or four years of what was the drug of choice for first time treatments.
- thanks!
- My only concern is that I feel Dr. Brander's comments were much too laid back. Although important characteristics of the virus are still unknown, using words like 'it might be a good idea to... you could... maybe...' is not only unhelpful, it's dangerous. She should not be concerned about causing us to feel worried or scared by using stronger language. We are already plenty worried and scared. She should err on the side of caution and tell people to wear masks, where to find instructions to make them, and how to not contaminate yourself taking them off (as Dr. Leclair explained about gloves); tell people how to get exercise and do calming activities indoors -- not everyone lives in a sparsely populated neighborhood where the risk of being outside is low(er); tell us how to disinfect food packaging correctly (although packaging is a small risk, it's not no risk, and the disinfecting process is effective and not difficult), etc. As we know, advice from the CDC et al. changes constantly, but always toward taking LESS risk. Dr. Brander should not be conveying the idea that certain risks are OK based on what we currently know. I was really surprised and dismayed to hear her say more than once that she was more worried about people not getting enough exercise than taking a risk by leaving their homes.

From the two webinars, I think we would benefit much more from a nutritionist or reputable naturopath who can provide concrete, proven information for strengthening the lungs, heart, thymus gland, etc. and overall mental and physical health (breathing exercises, gentle movement, simple meditation/visualization, etc.). These things are zero risk and lots of benefit for everyone at any time in one's life. I'd also like to add that while I greatly appreciate Dr. Mato's candor and expertise (and I learn a lot from him) I don't think 'this crisis will end on a scale of months' for people at high risk. The vaccine has to 1) be from killed cells, 2) be highly effective (which few are), and 3) be widely used. In addition, the virus needs to not become too mischievous in it's inclination to mutate. And then there is the expected rebound this fall/winter. For people at high risk, we will need to manage this situation for much longer than a few months, and we should understand that reality and prepare as best we can. Profound thanks for everything you do. Be well.

- Some of the 4/3 webinar was a repeat of the 3/27 webinar and it would be good to only bring those topics up when needed in the context of new questions.
- Replace Dr. Brander. In both webinars she gave long-winded replies that didn't answer the question asked. Irritating, frustrating, and not helpful. Meanwhile, the other panelists are great!
- Not sure I got the answer on handling mail and newspapers - could we have a summary of best practices?
- More new material needed. This is a sophisticated audience, with very high % of return participants. We can handle challenging material. What do we do if we get sick? What sketchy drugs should we take? What if things go bad? What off-label options should we pursue?
- Let's move on from testing and trying not to get COVID-19. What should a CLL patient do if s/he begins exhibiting symptoms? Does s/he need to be hospitalized immediately? When blood oxygen levels fall below a certain point? Some other trigger? And what if the caregiver begins to exhibit symptoms? Should s/he try to move out? Should the CLL patient immediately be tested?
I would have liked more specific info. on how long you should avoid touching various materials, ie. paper, rubber, etc. It was difficult to hear half way through the webinar. Volume decreased. If possible, would prefer to have another mtg. and to cut the mtg time shorter. A lot of good information. Thank you.

I wanted to view Dr. LeClair's diagram of something about the virus, but it showed up too small, and I couldn't tell what was what on it. I would have liked it to be a larger part of her slide.

I thought Dr. Leclair's portion was way too technical and I'm a geeky type person who usually enjoys that kind of presentation.

I needed longer to fill out the online forms. Hate to spend moments of conference time, though. Slow reader. I guess some managed.

I messed some of the testing for COVID-19 but using antibodies IgG and IgM sounds rather poor at best. Any work on a better methods than the PCR method being used now which is not a simple lab analysis? Your two MD's were great again. Their exact wording to answers is a pleasure to hear - they are both very smart.

I appreciate these meetings. It is a nice way to stay connected with developments especially tailored to people who are in the same boat. I may have missed it today but what is the progress in arranging local virtual support groups or other virtual small group meetings?

I appreciate all you are doing! That being said, I think the panel needs to keep their answers more concise.

I am not sure when to get tested. At what stage of the disease should one be tested? When breathing becomes difficult? When fever is high? What symptoms warrant a test? I know exposure or travel, but I am staying home.

Great seminar! It allows me to be connected to the CLL Society since I am not able to attend the monthly support group. Great panel and very helpful information about COVID-19 and overall relation to CLL. Thank you Brian, Patty (the real force behind this!) and to your panel of experts! One suggestion is that you take a bit more time in alerting meeting participants that the questioner is about to come up, how it works and if there is any way to slow it down a bit so that you are able to give people time to answer the questions. In my case, I had to step away to the restroom not realizing that the questions you mentioned were coming up were for the survey. I thought it pertained to general questions the public was sending in and I missed the survey. By the way, now anytime I hear on TV....’we are in this together’ I think of you two. Much love to you both.

Great program. Don't need to repeat so much from previous call. Thanks!!

Great info Thank You Doctors. Can you leave the survey's up just a little longer. The 2nd survey time limit was a little short. All in all in all great job.

Great discussion. In future meetings, specific case studies may be helpful.

Given that you have collated most questions in advance, it would be helpful if you could use a minute in the opening remarks to identify broadly the primary Q that will be covered in Q&A. Thanks.

Given that 87% were returnees, I thought too much time at the beginning was devoted to testing. Felt like 10 minutes. The questions are the most helpful so I'd like to maximize those more so in the future.

Don't repeat info from the prior week.

Are we yet seeing any subset mortality data for CLL patients infected with Covid-19? What suggestions can be drawn regarding potential for survival, with respect to stages or treatment of CLL, once infected with this novel coronavirus?

A rigorous discussion of how to de-virus paper goods coming into the house would be helpful. Is dry heat effective? If so, how hot, how long?
• A bit too much repetition from some participants, especially Dr Leclair. I really enjoyed the format. I had not had the opportunity to see the initial discussion last week, but will certainly view the taped version soon. In my humble opinion, it may be advantageous to accompany future calls with adding slightly opinions from varying disciplines and supportive care facets - such as high admitting MD's, PharmD/Pharmacists, NP or PA, floor nurses, etc. It may create dialogue regarding topics or ideas that may otherwise not have been discussed. Maybe C-suite personnel as well in order to discuss what the future may look like - with so much uncertainty, it may possibly be synergistic and therapeutic to add. Just a thought. It's Friday and I'm bloviating. Thanks so much for setting these up - they are very beneficial.

Misc

• Transmission was spotty quite a bit of the time - don't know if that was my technology or yours....
• I had trouble getting into the session even though I had signed up several days ago. I finally completely re-signed up again.
• First of all THANKS to the Dr's for taking the time to educate us and put some calm in our lives. I am newly dx (#months). Needless to say I am scared under normal circumstances and being a Breast Cancer survivor with this dx, I felt DOOMED with the Virus taking over. I would like to know about more supplements/vitamins/foods that may give us a better advantage to stay healthy. Also I wonder if its true to drink your beverages warm? I love ice in my drinks but will change if that is the case. Don't really like my VODKA warm. LOL Thanks again to each of you for taking the time to help us.
CLL Society COVID-19 Virtual Community Meeting Outcomes Report

Date: March 27, 2020

Total # Registered  1,171
Total # Attended    821

Evaluation Data

Approximately 34% of attendees completed the evaluation (n=283).

Of the respondents who selected “Other,” for the question “Which best describes your role with CLL?”, three were from the pharmaceutical industry, two were patients, one was a scientist, and the last person wrote nonprofit.
Please see the responses for people who selected Other for the question, “What topics around COVID-19 in future community meetings would you want us to include?”
Medical questions:

- More CLL specific information that is not available from other health experts. Such as relevant and specific info on CLL cases and their outcomes, testing, vaccines for immunocompromised, antibodies, etc.
- Knowing when to seek help.
- If I get COVID symptoms, at what point do I seek emergency help?
- As a CLL patient, do I have to expect a more severe course of covid-19? Is there a higher probability for that?
- Some specific examples of patients at different stages.
- Specifically, if my spouse (currently watch and wait with a strong immune system, slightly elevated white blood cell count) were to contract the virus and get to the point of needing to go to hospital what would we do to get treatment as soon as possible?
- Treatment of severe COVID-19, including anti-IL-6 monoclonals
- I believe Dr Leclair briefly touched on this: I'm interested in learning more about the physiology of a virus works in a patient. How does it replicate? How does the body respond/hyper-respond? How will therapies or vaccines work once administered?
- If we test positive for COVID-19, what is the likelihood we will have a mild case, a moderate case or a severe case requiring ICU treatment? I know we are in a high-risk category, just was wondering how high that risk is for requiring intubation?
- What should a CLL patient hospitalized with COVID-19 request, in addition to a possible IVIG infusion?
- Any new data specifically about CLL and covid-19

Medicine:

- Discuss the pro’s and con's of discontinuing Rx’s such as Imbrutinim with complete remission to reduce side effects/cost
- Getting 90 days supply of CLL drugs & getting *stash* scripts of antibiotics, antivirals plus - an emergency kit of basics without all the emails.

Other

- When the stay at home bans are lifted; precautions we still need to take.
- How to clean items (groceries) that need to come into the house
- Mental state

Verbatim Feedback

All of the following comments were transcribed verbatim from the evaluation survey of the CLL Society’s first COVID-19 Virtual Community Meeting. They have been organized based on type of feedback. These statements were provided in response to the question, “Please include any additional comments about today’s webinar.”

Positive/Affirming
• Overall EXCELLENT!! I appreciated Dr Koffman presenting the questions, many I would not have thought to address. The panel was fantastic as they provided straight forward information that was geared to me, the patient.
• Very well done; far more informative than the LLS webinar yesterday because it was specific to CLL only.
• Very informative, loved the chart per Dr LeClair explaining IgG and IgM level in response to infections etc.
• Susan LeClair’s explanation of testing and false readings is the best I have heard. Wish the general public was more informed by the media.
• The entire meeting was great and the testing overview was especially great! The testing overview was superb. I read a lot of medical journals and research. She did a fantastic job explaining the testing and how to ensure all the details are resolved.
• This was great. Very helpful - thank you! PS Dr Mato was great.
• Both the clinicians were A+ I've seen Dr. Mato before but I believe his knowledge and thoughts were insightful. His comment about FDA getting their act together for clinical trials for COVID-19 was great and the hope they can keep it up. I hope so too. I'm sorry I don't remember the name of the female doctor but she was outstanding as well. Her comment about staying out of doctor's office needs to be said more often during these times to try to not become infected.
• It was an excellent presentation. I appreciated hearing Tom Henry and Dr. LeClair’s input on COVID19 tests and potential treatments. That helped sort out why finding a safe and effective treatment for this virus is not that easy. Dr. Mato and Dr. Brander were likewise very good at explaining CLL-specific concerns. Look forward to next Friday's virtual meeting. Thanks!
• Many thanks to Kr. Koffman, Patricia and the panelists. Connections to and advice from the experts is tremendously helpful.
• I loved the 4 points at the end, they changed the way I now think about the pandemic and miraculously they also reduced my anxiety and changed my behavior. I'll never forget that advice.
• You covered all of the above but updates on all appreciated
• Thank you Brian - I loved the advice of gathering information from WHO, our state and local government and to turn the news off.
• Thank you for providing this very valuable information to the CLL community. All of the expert presenters were the best!!
• Thank you for providing this program and for scheduling another one next week.
• Thank you for doing this. It filled in some of my blanks and helped to verify some things I had already heard.
• The CLL society is an amazing organization.
• Wonderful, educational, and a spiritual uplift. Thank you!
• It was so good to know there were 1100 other people in similar circumstances and to hear from experts.
• It was wonderful. For the first time, I felt as if someone understood me and was speaking to me and my needs and concerns. Thank you so much!
• Wonderful speakers, all!
• Wonderful meeting. Thank you for giving us the opportunity to receive information from those we can trust. We hear so many different directions right now.
• Well organized, very good panel. Well done.
• Very well done, with knowledge, comes more arsenal for the fight.
• Looking forward to the session next week. Found this session informative.
• Very informative presentation of the facts and responses to questions. Many thanks.
• Very helpful, thank you all, I am very grateful for your work with us CLLers
• Very helpful! Well done! Thank you!
• Very empowering. Thank you.
• It was wonderful... thank you so much for offering this to us. I learned a lot and information is key!!
• Great service and excellent presenters! I enjoyed the fact that all the presenters were not necessarily on the same page. It was more real and less scripted.
• Today's meeting was excellent and useful. Everything was clearly explained and pertinent. I think that we are, as a group, educated and intelligent and it is good to be treated that way; I am looking forward to the meeting next week. I assume that the situation will have evolved somewhat by then. As a Washingtonian who consulted with him, I am especially looking forward to Dr. Page's comments.
• The presentation was very helpful. I am at home and feel this is the appropriate place to be for now. It was nice to see how other people are dealing with this crisis and it made me feel much more comfortable with the decision I have made. Thanks again for putting this on and I look forward to the local group Zoom meeting when it gets set up.
• The meeting was very helpful and interesting. We learned many new things. Thank you all very much!
• Thank you so much to everyone for taking time to do this virtual meeting! It was good to see the interaction between everyone and hear what everyone had to say. It was a bonus to see Dr. Mato and hear his views on the situation, since he was my CLL specialist at Penn Med prior to his move to MSK. Dr. LeClair had some great advice regarding anxiety. Many thanks to Brian Koffman for founding the CLL Society and for his ongoing commitment to CLL, as both a CLL patient and doctor. I'm looking forward to the next community meeting and will do my best to attend it! Stay safe and stay well everyone! Thanks again!
• The meeting did a lot to alleviate my fears. Thank you.
• Loved the patient-centered approach of talking about questions more than powerpoint presentations. Kudos to the panel -- all were excellent!
• "Loved the meeting! A great, trustworthy source by the CLL Society and look forward to the next meeting!
• Thank so much to Brian, Patty and amazing panel!
• EXCELLENT JOB...VERY INFORMATIVE! Thank you Dr Koffman and panel
• Excellent forum. Very informative. Thank you for doing this for all of us in the CLL Society! Dr. Koffman, our hats are off to you for making this happen. You and your colleagues are amazing. My family and I look forward to the virtual meeting again next week. God bless you all.
• Thanks, as I was diagnosed only earlier this month, I appreciate all the informative
• Thanks for putting the program/call in together. It was terrific
• Thank you! This program filled in some gaps and made me feel more confident.
• Thank you for the excellent information. I look forward to listening in next week.
Thank you for putting on this meeting. So informative and I do appreciate all the information and being CLL related. Thanks again for all your help and reaching out to CLL patients.

Excellent. answered questions I had, plus more. Every expert was clear, honest and made me feel more confident that I can manage myself, my CLL in this time of corona virus. Just hearing the responses regarding immunity, testing, IVIG helped me understand what I need to do, what questions still need to be addressed in terms of CLL and Covid-19. Thank you to the CLL Society, and the professionals who gave their time during this crisis.

Huge thanks once again to Dr Koffman and his team for heroic work keeping us all informed, and keeping us as positive as the facts allow!

Have attended CLL webinars for years; this was one of the most informative / best I have experienced. Thanks

Great program - Keep Up the Great Work.

Great discussion and a huge thanks for the CLL Society and faculty. Such a wealth of knowledge dedicated to this subject!

Feel better about the availability of ibrutinib.

Excellent. We appreciate having material for an educated audience. It wasn't 'dumbed down' like some other programs that we have participated in.

Good balance between all of the speakers, and all were excellent. Thanks

Firsts, excellent program...very informative...all the presenters were excellent...could it be shared on other coronavirus websites like the CDC's, John Hopkins University’s?

Although there are many unanswered questions, I was comforted by the clarity, honesty and professionalism of the panel. Thank you

Appreciated having the different perspectives. Reassured me about the decisions I am making about precautions I am taking.

Suggestions: Content & Speakers

Would like a little more emphasis on the science of immune system response/suppression

Would like to hear more about cll patients who have had Covid19 and how they manage the virus. Thank you

Very well coordinated. My questions were basically answered. As we develop more information, it may be helpful to provide some specific examples from doctors treating patients in hot spots.

Very informative! Next, I'd like to hear about some specific cases of patients and how they have handled their own daily routine whether they are receiving treatment or are in watch and wait.

Perhaps address the international audience listening. I realise you are an American organisation but your reach is far beyond your borders.

Today was really informative. Thank you so much. I'm still not really clear on how to stay protected. For example, should we be socially distancing from the family member who is going to the market? Is it okay to visit other people who are also staying at home? If a family member was tested positive, or suspected to have been positive, how long should we avoid them? Thank you!
The question about the UK's Bloodwise recommendation for patients and household members to 'shield' for 120 days (including not going outdoors for exercise) was asked, but not answered. Does the US expert team concur with that recommendation?

As a category, convalescent plasma harvesting seems different than other 'promising treatments.' I’d like to hear the experts address the clinical efficacy of this, as well as the barriers to delivering it to populations of patients at various risk levels. Would it be contraindicated for some patients?

The doctor that talked about false positive testing was not correct and created more anxiety than decreasing it.

Thank you to all of the presenters! Is there a link for Friday’s podcast that can be shared, maybe with the link to register for the next one. A question someone asked me I have not seen addressed, probably because internationally people are scrambling to just get past the first wave of this, is whether people can recover, be exposed, and catch this again or are people relapsing.

So great to just be together with everyone. Answered some questions that I never knew I had. Practical information that I can use right away. Makes me feel more hopeful. I would like to hear about any cases of CLL patients that have Covid-19 and how the fared. It was helpful to hear that anxiety is a normal response and you just have to roll with it. Thank you very much. Stay safe and stay well.

So little is still known about COVID-19, the doctors and other commentators didn’t have that much they could advise us on yet, especially for patients with CLL. Although, the CLL Society wants us to be strong together, at this point we are still on our own going forward. I hope we all stay well.

Perhaps by next week it would be helpful to hear if any CLL patients have contracted COVID-19 and how they responded.

It was great having information and questions answered. However kind of frustrating that there were so many equivocal answers. Everything depends.

I was still unclear on what I should be doing in regards to protecting myself the UK site Blood wise was quite clear and I was wondering if CLL society took the same view regarding a prolonged isolation

A little suggestion: If a presenter needs to cough, please 'walk the walk' and cough into an elbow, tissue, etc. - not a hand. It's critical to lead by example.

Great meeting. Can you remind us in words about the presenters take aways at the end, including your own very good one on anxiety. I remember Susan had 4 good ones. Thanks again.

Did not think that the question about what precautions one’s partner should take was answered with much clarity.

Misc:

I wasn't sure if the questions feature was on or if all questions had to be submitted beforehand, thanks for all you do.

Zoom worked very well

Very difficult to get into the meeting. Instructions were terrible. Assumed that you had Zoom. Assumed that you understood all technical terms. Great start.
• Needs to be more time to answer more questions
• UNABLE TO ANSWER QUESTIONS AT BEGINNING AND END. DID NOT SURFACE ON THE PAGE FOR ME. OTHER SLIDES WERE VISIBLE.
• The streaming kept freezing up so it was a bit hard to hear everything
• I clicked off because I was unsure if everyone could/could not see me. Lol. Please tell me that the participants aren’t in view at the zoom meeting. I plan on listening to recorded version.
• Great meeting. I needed just a little more time on the questions at the end so messed up my answer to the last Q4. I'll try harder next week. Thanks again