2020 Support Group Survey Outcomes Report

Total Completed: 441

Which best describes your role with CLL? Please select all that apply:

- CLL patient: 86.59%
- Caregiver to a CLL patient: 8.57%
- Loved one of CLL patient (but not the primary caregiver): 1.10%
- Healthcare professional: 2.42%
- Other, please specify: 1.32%

What is your gender?

- Male: 41.50%
- Female: 57.82%
- Prefer not to say: 0.45%
- Prefer to identify as: 0.23%
What is your age?

Range: 34 – 88 years old
Mean age: 64 years old
Mode age: 72 years old

Please specify your race and ethnicity; select all that apply:

- White or Caucasian: 91.96%
- Hispanic or Latino: 2.48%
- Black or African American: 1.34%
- Asian or Asian American: 0.67%
- Indigenous, First Nation, American Indian or Alaska Native: 0.22%
- Prefer not to say: 2.90%
- Don’t know / Not sure: 0.45%

What is your current caregiver status?

- I don't have a caregiver: 45.12%
- Prefer not to say: 1.13%
- Don’t know/Not sure: 3.63%
- I am or have a caregiver that lives nearby: 2.27%
- I am or have a live-in caregiver: 47.88%
What is your or the CLL patient’s status of treatment for CLL?

<table>
<thead>
<tr>
<th>Status</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have not had treatment (also referred to as treatment naive or watch and wait)</td>
<td>179</td>
<td>40.59%</td>
</tr>
<tr>
<td>I am currently being treated for the first time or I have completed my first treatment</td>
<td>133</td>
<td>30.16%</td>
</tr>
<tr>
<td>I have had two or more treatments or am currently being treated for the second time</td>
<td>119</td>
<td>26.98%</td>
</tr>
<tr>
<td>Don’t know/Not sure</td>
<td>6</td>
<td>1.36%</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>4</td>
<td>0.91%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>441</td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

I am more comfortable with my or the patient’s CLL diagnosis since attending my local CLL Society Support Group.
I feel more supported by a new network of friends whose lives also have been touched by CLL since attending my local CLL Society Support Group.

I am more knowledgeable about CLL since attending my local CLL Society Support Group.
I am more involved in my or the patient’s CLL management since attending my local CLL Society Support Group.

I have changed the management of my or the patient’s CLL since attending my local CLL Society Support Group (i.e., different testing, treatments, or treatment teams).
I would recommend my local CLL Society Support Group to other CLL patients and families.

I am pleased with the leadership and facilitation of my local CLL Society Support Group.
Other Types of CLL-Focused Meetings I would be interested in attending a CLL-focused support group that is organized around a shared characteristic, interest, or treatment in addition to or instead of by geographic location. This could be based on age, treatment status, caregiver-focused, etc.

I would be interested in the following CLL-focused support group meeting; please select all that apply:

<table>
<thead>
<tr>
<th>Option</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>CLL patients/caregivers under 50 years of age</td>
<td>24</td>
<td>3.16%</td>
</tr>
<tr>
<td>CLL patients/caregivers with young kids</td>
<td>10</td>
<td>1.22%</td>
</tr>
<tr>
<td>Caregivers</td>
<td>20</td>
<td>2.44%</td>
</tr>
<tr>
<td>CLL patients without caregivers</td>
<td>73</td>
<td>8.62%</td>
</tr>
<tr>
<td>Watch and Wait</td>
<td>125</td>
<td>14.47%</td>
</tr>
<tr>
<td>Specific Drug treatment – such as ibrutinib, venetoclax, etc.</td>
<td>219</td>
<td>26.83%</td>
</tr>
<tr>
<td>CAR-T Therapy</td>
<td>95</td>
<td>12.52%</td>
</tr>
<tr>
<td>Transplant</td>
<td>13</td>
<td>1.71%</td>
</tr>
<tr>
<td>Clinical trials</td>
<td>130</td>
<td>17.13%</td>
</tr>
<tr>
<td>I am not interested in any of these options</td>
<td>29</td>
<td>3.62%</td>
</tr>
<tr>
<td>Other, please specify:</td>
<td>21</td>
<td>2.77%</td>
</tr>
</tbody>
</table>

Total 759 100%
Other, please specify:

- Long term patients
- Closer knit group that actually got to know one another, group is too far away
- Assembling Medical Teams / 2nd/3rd Opinion-givers
- Perhaps expand the CLL Patients under 50 to 55 or 60 (I'm just 53-I still feel significantly younger than most of the other people diagnosed/in a different stage of life)
- Lifestyle, nutrition, and holistic/integrative approaches to CLL treatment and management.
- IVIG treatment
- Research and Treatment focused. The local CLL is good about it, and also about emotional support. But a source for lots of medical info would be good.
- Selecting a first treatment
- Emotional problems that arise
- Richters
- Ketogenic Diet, more knowledge about immune system and lymph nodes
- NUTRITION
- short term & long term effects; COVID vaccine
- options for patients on their 3rd treatment
- Non-Standard alternative treatments
- If I were in treatment I might like a group of persons taking that form of treatment.
- 17 p deleted
- Treatments in general, staying healthy while having CLL
- co-morbidities: Skin cancer, Diabetes
- 1) Over 70; 2) Living with another primary cancer;
- What’s next. That is, a group that focuses on sequencing CLL treatments

I would be interested in facilitating a Support Group based on a CLL-related shared interest: Other Option: Yes, please include your name, email, and interest:

- Norm Ward
  sidcerely@comcast.net
- NOTE: I am very new to CLL and CLL-support groups, and know little, but could spend time assisting. I’m used to hosting Zoom meetings, and to moderating discussions in other fields. I have some, but limited, spare time. Jonathan Khuner jkhuner@sonic.net 510.593.9291
- Julie Hess
- Pete Davis davis299@gmail.com
- shadowkhq@icloud.com - Watch & Wait
- Gary Calleo vnccall@yahoo.com
- Brett Modesti smodesti18@gmail.com Caregivers
- Frank Stein, 122 Shagbark Way, Fairport, NY 14450
- lenkeck@comcast.net
- Dan Patterson danpatterson@nc.rr.com plains3545@gmail.com
- Larry Marion, help with ibrutinib and/or venetoclax
Verbatim Feedback

All of the following comments were transcribed verbatim from the 2020 Support Group Survey. They have been organized based on type of feedback. These statements were provided in response to the question, “Please let us know how we could improve virtual support group meetings or any other comments or feedback you would like to provide. All survey responses are confidential, unless you would like to include your name with your response.”

Positive / Affirming:

- I am very comfortable with the support group that I attend. And now with zoom. I now have a CLL specialist as my Dr., because of attending my CLL support group. A member told us of Dr. Awan moving into the Dallas area. I changed to him. I would not have known if I did not attend. Dr. Awan also came to one of our meetings to talk and meet us. I am fortunate to be one of his patients now. Elise Cary and Judy Williams do a great job leading our group. I would like to say when I first was diagnosed with CLL I did not know about CLL specialists. It would have helped me if I knew. The CLL society does a good job in communicating this to new diagnosed patients if they come to the site. I did not know about CLL society until I did a lot of research on my own. William Hassel
- All that CLL Society does is appreciated! My journey would have been much different without finding the CLL Society soon after diagnosis.
- Appreciate all you do thank you
- Appreciate what you do to support CLL patients. Have a great day!
- Attended Nashville group for first time. Excellent. Would have rated items higher re gaining knowledge but husband has had CLL for 8 years and I do a lot of research and reading, so I did not gain that, but as a caregiver, I gained moral support, and that is what I needed. Thank you for the support groups. Excellent!!!
- Christina and Haleh are terrific
- CLL Society transitioned smoothly to online support groups. Keep up the good work!
- Currently well handled.
- Denver CLL Support group is great.
- Excellent support from our two local leaders, Laura and Nancy. They have been well trained by the Society and see to it that the CLL Society’s goals and meeting procedures are respected. Everyone feels comfortable sharing their personal journeys. Since we also appear to be patients at the James Cancer Center in Columbus, OH too, it’s good to share perspectives on what the James are thinking about CLL patient care, COVID, etc. Overall, a worthwhile experience and we’re all looking forward to the day when we can meet to continue these sessions in person. Nice job!
- I ABSOLUTELY LOVE THIS GROUP and I am so glad I found it!!!! This group has been a game changer for me. I am so appreciative. I LOVE THIS GROUP!
- I am getting 100% support and knowledge from CLL Society.
- I am grateful for the work the CLL society has done. I am also grateful for the work that the Central Florida leadership has done. My CLL is in remission, but I continue to read the CLL
Society's online info. I have found assurance, a camaraderie among fellow CLLers, & important up to date info from trustworthy professionals.

- I am so grateful for our support leaders. They are so wonderful and supportive. Cheers
- I am very happy with all you do. It has helped tremendously. You have truly increased my education on CLL.
- I enjoy listening to the others who have stories to share. The group leaders know their stuff in regards to CLL.
- I enjoy the meetings and I’ve established a good friendship with a fellow member of the group.
- I have benefited from attending and am glad such a group is available as it is significantly encouraging and informative as well. I have found it a very positive component in my CLL journey and am thankful to those who spend so much time and effort to put it all together every month.
- I live right in the middle of the Orange County and City of Hope support groups. I consider both of them my home group. They are very important to my support. Both groups have great leaders and members.
- I really can’t say enough great things about the CCL Society. I promote it every chance I get. I also think the Moderators do a great Job. WE GOTTA GIVE A SHOUT OUT! to the people behind the scenes. A big WooRaah to Patti, the videographer or tech person, and last but far from least Barbara and Howard. Great Job!
- I think it is a wonderful group. I have only attended once due to children activities and my job on Saturdays.
  Hopefully i will attend more
- I think that the leaders of my support group have done an excellent job of providing up to date information and support.
- I want to give a BIG kudos to Albie who facilitates the Rochester support group. She does a GREAT job!
- I was diagnosed in 2005 but did not start participating in the DC CLL Society until 6 months ago. I have learned so much more about my disease in these past six months. I am so very grateful for this group.
- I would like to express my deepest appreciation to Lori Kubik and her husband. As the leader of the group, she is an absolute star. Her dedication, knowledge and patience are without power and she has improved our outlook regarding CLL significantly.
- Incredibly appreciative for the Boston CLL support group.
- It’s amazing what a wonderful job Brian Koffman has done. The 2 leaders of our support group are amazing and serve as an example of what other chapters should be doing.
- Keep up the good work. Thanks.
- Lori Kubic has been extremely helpful in connecting me with support and very quick to respond to any questions.
  my Boston co facilitators, Judy Cody and Bob Barton, are fabulous. an amazing team. making sure each support group has co facilitators is a great thing.
- Our group is very good and the leader, Randy Parker, keeps us on tract to start and end, and includes everybody in the group. We read the bloodline together every time. I like the format and the way that Randy gets things done but is not pushy. Thank you, Randy, and CLL Society.
- So glad you’re here!
- Thank you all, can’t do this without your support. Can’t thank you enough. You are just awesome.
- Thank you Dr. Koffman for all of your work in supporting the CLL community. Both you, Patty, and the rest of your team are making a difference for us with CLL.
- Thank you for all you do.
- Thank you for all your efforts. Happy Healthy New Year.
Thank you for everything you do. As a patient, you make me feel stronger and supported.

Thank you for the amazing resources, informative medical advances and work you do to educate, and teach us to advocate for ourselves and support one another with hope and compassion.

Thank you to the CLL Society for all that you do for patients and care givers, it is a light in what could be a dark situation. Happy Holidays to everyone!

Thanks for your support of CLL patients and their care partners/care givers.

The DC CLL Society has been such a wonderful experience for me. I have learned so much and met so many wonderful, well informed and kind people.

The DFW group has been very informative and very supportive. Love the way Elise and Judy run the meeting and the guests they line up has been wonderful. This is a very supportive group and I feel very fortunate that I found this group.

The facilitators of my support group do an excellent job.

The group I attend is extremely helpful and knowledgeable. I am very grateful for both the leader and the members.

The group is always very positive and very encouraging. They provide a great deal of valuable information.

The Washington, D.C. group has been exceptional since it began. We have a very well-educated group; in professional areas as well as experience with CLL. The experience and knowledge among members is of great value. The leadership has changed as years have passed, but the quality has remained high. New members are welcomed and invited to share if they wish... and a round of updates from each member is offered. Specific questions raised by members, often the new ones, result in shared experiences and memories from the more experienced members. Special guests increase the wealth of knowledge. I believe that the people who attend give the newly diagnosed tremendous support, which decreases levels of anxiety, and give direction to their challenges and goals.

I am grateful for the CLL Society support group. It’s comforting to be with people who understand. We all support each other. Linda is ‘the best’. She is a wonderful facilitator. Thank you, Dr. Koffman and Mrs. Koffman for your dedication and caring manner. Continued success and good health always. Cathe

This support group is my lifeline. Not only have they helped me to put my cancer in perspective, but they are also my main source of information of the developments in treatment and management of the disease. Even though I work with a doctor who is a CLL specialist I receive very little guidance there. Without the CLL Society and the hard work of Dr. Koffman I would feel left in the dark.

Virtual Meetings:

The meeting consists of each person telling their story, each month. It’s repetitive and useless. Where’s the expert information, where’s the dialog about CLL and COVID, about the value and risks of the vaccine, about CLL, COVID and anxiety or depression? I see no value in the current meeting structure.

Enjoy the group – do miss meeting in person. Zoom is a good alternative.

The virtual meetings are proving to be excellent. Our 2 facilitators are very good at handling the details and schedule. I especially like when we have an expert in some aspect of CLL, care, etc.

Kathleen H. Quinn

Our virtual meetings have been very good!

Actually, I prefer to attend meetings via Zoom than to meet in person. I would have a long drive if we met in person.

An effective way to provide support and education for CLL/SLL diagnosed individuals. We are not alone.
• Even though virtual meetings are how we need to meet, I think they are allowing more people to attend. It's a good platform. We have participants from all over the country which keeps it interesting.

• For the group that I attend, change the time to 10:00 or 11:00 a.m. and keep the meeting to one hour. When COVID is under control, if I attend, I would have to drive over 2 1/2 hours to the meeting, then 2 1/2 hours home. During standard time months, that would inevitably mean driving at night for a person with serious cataracts who cannot have surgery due to sudden onset, very aggressive CLL. When COVID is under control, I would sincerely appreciate if virtual continues to be an option as I will not be able to attend very often at all due to distance and time.

• Having virtual meetings has allowed me to more easily attend more than one group's meeting without having to travel.

• I actually prefer the meetings to be virtual. My group is too far away for me to attend if and when we discontinue meeting virtually.

• I am looking forward to meeting again in person, even though I have to travel 2 1/2 hours to the meeting. The virtual meetings have been fine. I especially enjoy them because the 'snowbirds' who only attend the in-person meetings in the winter months, can attend year around. Olivia Rowe

• I am so pleased with the Zoom support group meetings. Always good information on things I would have never known about CLL. Sometimes when your home and worried about your problems, it's so nice to listen and talk to others with the same concerns. A good meeting with Stephen is the place to be. Thanks for being here for me. From Ann

• I am very grateful to be able to participate in the Boston Support group. Before it was possible to participate by Zoom, I could not attend as I live 100 miles away from Boston.

• I am very thankful that these meetings are virtual. I live in Maryland and I am happy to be part of the Philadelphia support group now.

• I hope the meetings will continue via Zoom once the pandemic is 'over'. It is nice people can participate from any part of the country.

• I prefer the in-person meetings because the interaction between attendees is more spontaneous and personal. However, the Zoom meetings draw a much wider geographic participation.

• I think it would be valuable to continue at least some meetings on Zoom or some other virtual platform for two reasons: difficulty in getting somewhere outside your immediate area and the convenience of being comfortable in your own space. While it is not ideal to not meet in person, virtual meetings offer more privacy and allows a person in MA to go to a friendly meeting in DC where I have a connection.

• I think our meetings have gone well but looking forward to the day we can all meet in person again.

• I think we are doing the best we can under the circumstances. The virtual meetings will probably be the format for the future. We are unsure of any additional strains of the virus that might surface.

• In person meeting were great, however since they cannot be held at this time, virtual (Zoom) meetings are a good way to stay in touch.

• Keep the virtual option for all meetings even post COVID.

• Looking forward to in person meetings someday soon as well.

• My group's leaders handle the virtual format well. I have no suggestions for improvement. Deborah Manning

• Our virtual meetings are well-attended, and most people seem to be happy with the platform. I think that as we ease back into fact-to-face meetings that a hybrid meeting should be established as there are people hours away that could not make the trip.
• The virtual format is so very convenient. The attendees need a bit of coaching on how to participate - not wiggle their iPads the whole time, not getting up and down constantly, and other distractors.
• There are no support groups near me. I could not attend if it were not virtual. I hope these groups continue after the COVID virus is under control.
• Virtual meetings help to fill the void during the pandemic. There is so much information gained at each meeting and the world of treatments change so quickly it is necessary to meet to keep up. Newbies find out they are not alone and that is priceless.
• Virtual support group meetings by focus area sounds interesting although focus-area support groups would likely bee too difficult to implement/maintain in a 'live' setting post-COVID.
• We miss the opportunity of gathering with the support group. It was a fun time for us to get out together and meet with the other members.
• While I live close to the normal meeting location, the Zoom meetings have been a definite benefit for those who live a bit further away. Facilitators have done a great job in keeping the discussion focused. That's probably easier in the virtual format where there is less cross-talking. Meeting in person (when it's safe to do so) is definitely preferred as face-to-face contact is lacking when only seeing each other in small boxes. Having an MD as one of the facilitators is a definite plus for our group.
• I am pleased it is a virtual meeting as I would not be able to attend otherwise due to the distance.

Questions / Recommendations

• How do you seek out a second opinion on your treatment?
• (1) A specific topic/s to start the meeting. (2) A 1-hr time limit to meeting. One and 1/2 hours is too long to sit and interact with device.
• A food and supplement discussion would be interested.
• Continual and updated information on CLL and COVID!!! Studies, numbers, outcomes, experiences - anything. Vaccinations, prevention, treatment - anything.
• COVID-19 Vaccine Considerations
• Give new information available to CLL Support Group leaders. It is helpful to those of us who are not medically language proficient to know what the many acronyms out there mean. Our group is really very helpful but tends to get a little morose sometimes. I know it shouldn't be happy land, but more hopeful in nature
• I am a member of the Toronto CLL Support Group that is NOT part of the CLL Society. Since this appeared in the drop-down menu here, I am assuming there is another separate group. It would be good for the CLL Society to partner with other organizations such as Wellspring; Gilda's Club to avoid duplication.
• Lessen the length of the meeting to one hour.
• More webinars!
• A website page for each CLL local group – available on the main site, where they can post about upcoming events and learning opportunities. As a SMZL patient (splenic marginal zone), is there any way to include us somewhere? We're 2% of lymphomas. What happens if one of us transforms? I don't see much to help someone understand and transition to care of that. Overall, the Washington, DC CLL group was lifesaving. I wasn't getting good info from doctors and they gave me enough framework to figure out how to get the info I needed, and emotional support when I hadn't yet shared the news with my parents.
• I would like to find a support group for CLL in FL and or Miami...?
• It's great that the CLL Society continues to share monthly e-newsletters with Brian interviewing top specialists both about CLL and about COVID's impacts on CLL patients.
I wonder if there are opportunities to network between groups now that we are in the Zoom environment. Also, I notice the CLL Society asking for donations. Originally, I thought the group was funded by pharmaceutical companies. It might be helpful to communicate why funds are needed and what they support. Best wishes for a safe and healthy 2021, thank you for all you do.

Comments:

- I love the CLL group. However, sometimes during each person’s check in, some people speak excessively. Meeting routinely pass 2.5 hours. I would just suggest to everyone to be succinct. All participants are so nice and supportive.
- Meetings are great and informative; local support group meeting sometimes runs on a little bit too long (usually lasts 2 hours, but with a bit more strict moderating could be half hour shorter, easily.
- My support group has provided me with so much valuable information. I learned from other members about what kind of oncologist I needed. I have reached out to the group leader on several occasions with my personal concerns and fears.
- Nobody is really personal about how they feel. There’s talk about what therapy each of us is on but no one shares feeling about starting the therapy, if it made them sick and if it did what would they change, the struggles of getting to therapy, if they have a caregiver etc. I have learned from the group but have spent most of my time getting info from emails/webinars sent from the CLL Society and Patient Power. I will continue to go to the group.
- I love our local group but am also involved with 2, international support groups, (Blood Cancer Uncensored and Health Unlocked.
- I might be interested in facilitating a group focused on clinical trials. Linda Lannom 202-579-6583
- Terry Evans, and I would be interested in leading a group on Clinical Trials.
- I think that the recent attempt at advertising our groups is excellent and should be continued. The nature of these groups is that people come, and people go - we need a continuous stream of new folks to keep us going.

Miscellaneous:

- I'm fairly new on the CLL websites therefore I'm still learning. But I'm finding it very enlightening.
- I answered no to the last question because I already belong to a CLL Society group.
- I have SLL. But have been grouped in with CLL patients and groups.
- I say No to the last question only because I am so new to CLL and need time to digest some things.
- Just joined so still formulating point of view.
- Sylvia Fink, sfink6655@aol.com. Feel free to contact me.
- Thank you for the support. My oncologist, and CLL Specialist, Dr. Cheson retired rather suddenly... and if not for the CLL group of Washington, DC, I would have had much more difficulty finding a replacement. I have seen a Dr. Lai in the interim. Dr. Cheson retired, and A doctor Kieron Dunleavy will begin working as the new lead at Georgetown Univ Hospital, Lombardy Center. Dunleavy will head up the Lymphoma Dept... and hopefully will continue to advance the research of causes and therapies for CLL much like his predecessor, Dr. Cheson.
- I am an LLS volunteer and therefore I receive all their material as well. My job with LLS is patient, caregiver and hospital outreach.
- I am in treatment now for probably the 10th time and that was not one of the choices.
• One of the questions about current treatment status didn't offer an option relevant to my situation: I am R/R currently in my FOURTH treatment regimen. (It is soon to be completed.) The closest option on the list was 'in second treatment,' so I chose that as my response.

Facilitators:

• I would like to see more support from the CLL Society to provide speakers, topic ideas, and materials for the virtual meetings. Conducting virtual meetings are more challenging than 'in person' meetings. There is a much different dynamic that requires a 'core' purpose for the meeting and it is an increasingly difficult job to create meetings that have a topic which can sustain 1 1/2 hours of interaction via Zoom. The additional challenges of the Zoom meeting are the multiple methods by which attendees access the meeting (phones, I Pads, laptops, computers etc.).
• I am a Co-Facilitator. Not sure if you wanted my feedback. But I completed the survey just in case.
• I am already a Co-Facilitator of the SF CLL Society Group. Certain members would benefit from counseling before treatment with a CLL Society volunteer that has been through a similar treatment that they are considering.