

THE POWER OF CONNECTIVITY

2023

ANNUAL REPORT



CLL SOCIETY

THE POWER OF CONNECTIVITY

Anything is possible through The Power of Connectivity. CLL Society's desire is to reach every single person affected by chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL).

Building connections with our patient and care partner community, fellow patient-centered organizations, and healthcare professionals is a crucial element to achieving this. We aim to take an interconnected approach to further broadening our impact by implementing diverse approaches and reaching patients and care partners through multiple channels.

In 2023, our focus was on harnessing the power that is in connections. We established new programs to reach diverse demographics and strengthen connections with our existing patient audience to better learn their needs. Initiatives like Equitable Community Care Outreach are building inroads to the community healthcare setting to educate providers and patients we are not yet reaching. We have also bolstered our efforts to advocate for patient needs by collaborating with organizations whose goals align with ours to amplify impact.

Looking ahead, we are committed to deepening our connections with patients, care partners, healthcare professionals, and fellow patient-oriented organizations to improve patient lives. Because when we tackle ambitious goals together, the progress achieved surpasses anything we would accomplish individually.

Vision Statement

We envision a world in which the entire CLL/SLL community can equitably access quality education, support, and care, to lead healthier and richer lives.

Mission Statement

CLL Society is an inclusive, patient-centric, physician-curated nonprofit organization that addresses the unmet needs of the chronic lymphocytic leukemia and small lymphocytic lymphoma (CLL/SLL) community through patient education, advocacy, support, and research.





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*Left 2023. **Left 2024. ***Joined 2024



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EXECUTIVE STATEMENT

CLL Society envisions a world in which the entire CLL/SLL community can equitably access quality education, support, and care, to lead healthier and richer lives.

This is our official Vision Statement. As we began thinking about our priorities for 2023, we were proud of the progress we have made toward this vision by providing quality education, support, and care that allow those with CLL or SLL to lead healthier and richer lives. But we realized where we still have work to do is reaching the entire community.

About 200,000 people in the United States have a CLL or SLL diagnosis. Of those, approximately 20% are connected to care from a CLL expert. The remaining 80% are seen in the community setting by a general hematologist or oncologist who faces the challenge of staying current with changing treatment landscapes across multiple cancer types. In those settings, a disproportionate number of patients are being prescribed chemotherapy (CIT) rather than newer, often more effective, and better tolerated targeted frontline therapies. Additionally, these providers typically lack CLL resources to offer their patients. These are the patients that need us most. These are the people with whom we want to connect. Of course, patient data is highly protected, as it should be, leaving no easy pathway for us to build these connections. But since when have we shied away from a challenge? In response, we developed a comprehensive, multi-year Equitable Community Care Outreach (ECCO) plan, which launched in 2023, deploying multiple strategies to reach these most vulnerable patients with valuable information and resources, inviting them to join the CLL Society community and become one of the thousands of smart patients getting smart care. Harnessing the power of connectivity, we aim to address health equity by engaging with communities to reach the 80% of CLL patients who are treated by a general hematologist/oncologist rather than a CLL expert. We will not stop until we can say we have achieved our vision of reaching the entire CLL/SLL community.

At the same time, we continue to find innovative ways to serve those already here with educational and support programs that will enhance your lives and empower you to get your best care, while fighting for policies that will ensure equitable access to treatments and preserve avenues to innovation, and funding promising research to ensure an ever-improving treatment landscape.

We appreciate each and every one of you for your participation in our events, your feedback on our surveys, your volunteerism, and your financial generosity. We continue to become a stronger organization thanks to you.

Stay Strong. We are all connected. We are all in this together.



Brian Koffman, MDCM
Co-Founder



Carly Harrington, MEd, MBA
Executive Director



Steve Bloom
President & Chair



2023 IMPACT



\$822,960

donated by individuals to advance the mission of CLL Society



\$300,000

committed to scientific research specifically in CLL with formalized plans to grow grant funding through the CLL Society Research Program next year



726

new support group members connected with an empowering community of fellow patients and care partners



2,600+

individuals reached through CLL Society education events, empowering them with knowledge about their disease



97%

of Expert Access™ participants learned something new during their free, second opinion consultation with a world-renowned CLL expert physician



15

media outlets featured CLL Society as an expert voice on CLL matters







ESTABLISHING BONDS THROUGH SUPPORT AND EDUCATION

CLL Society support and education programs help patients and care partners navigate a CLL diagnosis, learn about treatment options, and provide reassurance that they are not alone on this journey.

“ ”

Even though I feel quite confident with my current treatment protocol, it was extremely helpful to speak to a CLL specialist through the Expert Access Program who could confirm our confidence, but also comment on future considerations and expectations. Having a specialist who sees so many patients like me was quite reassuring.

- Terry Ziegler

Living with CLL

PATIENT AND CARE PARTNER PROGRAMS

At the core of CLL Society's mission is the innate commitment to help every individual diagnosed with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL) receive the highest quality care in a rapidly evolving treatment landscape.

Providing comprehensive education and robust support by connecting not only with patients, but with care partners, family members, and loved ones, we position ourselves as dedicated partners on every step of their journey. When empowered with knowledge and a supportive community, we know that patient quality of life and longevity is improved.

Beyond our foundational programs that have a proven track record of meeting patient needs, we are continuously finding innovative ways to serve the CLL community. Each year, we launch new resources and programs inspired by our community members' crucial perspectives on the evolving needs of those impacted by this disease and designed to fortify links to currently underserved constituent groups.



THE CLL MEDICINE CABINET

By the end of 2023, nine drugs had received FDA approval for the treatment of CLL/SLL. Our CLL Medicine Cabinet contains the most crucial information for patients to know about each of these nine medications to help them understand their treatment options.

This resource is designed to increase an individual's comprehension of how different treatments work so that they have greater confidence in the shared decision-making process with their healthcare team.

Each medication in the CLL Medicine Cabinet includes a two-page patient-friendly fact sheet, a link to the FDA medication fact sheet, a compilation of all CLL Society educational content related to the drug, and information on financial resources. Launched in the Fall of 2023, CLL Society Medicine Cabinet sheets had been accessed thousands of times by the end of the year.

MEDICINE CABINET: IBRUTINIB
 Generic Name: Ibrutinib | Brand Name: Imbruvica
 Drug Classification: Covalent Bruton Tyrosine Kinase (BTK) Inhibitor

INDICATIONS FOR USE

- For CLL and SLL without TP53 deletion or TP53 mutation: Ibrutinib may be taken alone or in combination with another medication as an initial chronic treatment. When used as a combination therapy for frontline treatment, it is usually combined with either venetoclax, rituximab, or venetoclax and rituximab.
- For CLL and SLL with TP53 deletion or TP53 mutation: Ibrutinib may be taken alone or in combination with venetoclax as an initial chronic treatment, or alone as a maintenance or subsequent treatment.

ADMINISTRATION ROUTE
 Taken orally by mouth (swallow) as a capsule, tablet, or liquid form.

LENGTH OF TIME ADMINISTERED
 This medication should be taken indefinitely until either the disease progresses while on the medication (which would require switching to a medication to treat the CLL or SLL) or until certain unacceptable side effects occur requiring discontinuation of the drug.

DOING
 420 mg (one capsule per day), at the same time each day.

MISSED DOSE
 If a dose is missed by more than three hours, it should be skipped. Do not take the next dose at the regularly scheduled time. Do not take an extra dose to make up for the missed dose.

HOW TO TAKE

- Swallow the medicine whole.
- Take the medicine with or without food.
- Do not ingest any start-up, grapefruit juice, grapefruit, bitter orange, or pomelo products.

COMBINATION THERAPIES
 Can be used in combination with other medications (i.e., rituximab, rituximab, venetoclax).

COMMON SIDE EFFECTS
 Side effects can occur as a result of any medication, some of which may go away with time as your body adjusts to the new medication. Please notify your healthcare provider right away if any of the following side effects occur:

- Low red blood cell count, low white blood cell count, or low platelet count
- Irregular heartbeat (heart palpitations or racing heartbeat)
- Respiratory infection
- Shortness of breath
- Diarrhea
- Constipation
- Nausea and vomiting
- Stomach pain
- Decreased appetite
- Mouth sores
- Fatigue or tiredness
- Muscle, joint, or bone pain
- Blushing or bleeding
- Swelling
- Swelling of the legs and feet

Side effects not mentioned above may also occur. Notify your healthcare provider of any other unusual symptoms, as they may be able to help you adjust ways to prevent or reduce certain side effects.

MEDICINE CABINET: ZANUBRUTINIB
 Generic Name: Zanubrutinib | Brand Name: Brukinia
 Drug Classification: Covalent Bruton Tyrosine Kinase (BTK) Inhibitor

INDICATIONS FOR USE

- For CLL and SLL without TP53 deletion or TP53 mutation: Zanubrutinib may be taken alone as a preferred initial (first-line) treatment, or alone as a maintenance or second-line treatment.
- For CLL and SLL with TP53 deletion or TP53 mutation: Zanubrutinib may be taken alone as a preferred initial (first-line) treatment, or alone as a second- or third-line treatment.

ADMINISTRATION ROUTE
 Taken orally by mouth (in capsule form).

LENGTH OF TIME ADMINISTERED
 This medication should be taken indefinitely until either the disease progresses while on the medication (which would require switching to a medication to treat the CLL or SLL) or until certain unacceptable side effects occur requiring discontinuation of the drug.

DOING
 800 mg orally twice a day (twice every 12 hours) or 200 mg orally once a day (twice every 12 hours).

MISSED DOSE
 If a dose is missed by more than three hours, it should be skipped. Take the next dose at the regularly scheduled time. Do not take an extra dose to make up for the missed dose.

HOW TO TAKE THIS MEDICATION

- Swallow the medication whole with water. Do not chew, break open, or crush.
- May be taken with or without food.
- Do not ingest any start-up, grapefruit, bitter orange, or pomelo products.

COMBINATION THERAPIES
 No combination therapies are yet recommended.

COMMON SIDE EFFECTS
 Side effects can occur because of any medication, some of which may go away with time as your body adjusts to the new medication. Please notify your healthcare provider right away if any of the following side effects occur:

- Low neutrophil count, low white blood cell count, or low platelet count
- Shortness of breath
- Fatigue
- Muscle, joint, or bone pain
- Blushing or bleeding
- Diarrhea
- Swelling

Side effects not mentioned above may also occur. Notify your healthcare provider of any other unusual symptoms, as they may be able to help you adjust ways to prevent or reduce certain side effects.

MANAGING COMMON SIDE EFFECTS
 Some side effects are more common than others, many of which will go away after a short period of time after starting on the medication. It is important to talk to your healthcare provider to discuss if you might be able to manage side effects in the short term in order to stay on the therapy until your body has time to adjust to the new medication. Here are some possible ways to help manage some of the most common side effects of zanubrutinib in combination with your healthcare provider:

- Increase your fluid intake.
- Take over-the-counter medications (such as Imodium) per package instructions.
- Eat bland food (such as bananas, rice, applesauce, toast, or plain pasta).

Some side effects are more common than others, many of which will go away after a short period of time after starting on the medication. It is important to talk to your healthcare provider to discuss if you might be able to manage side effects in the short term in order to stay on the therapy until your body has time to adjust to the new medication. Here are some possible ways to help manage some of the most common side effects of zanubrutinib in combination with your healthcare provider.



MEDICINE CABINET: PIRTOBRUTINIB
 Generic Name: Pirtobrutinib | Brand Name: Jaypirca
 Drug Classification: Non-Covalent Bruton Tyrosine Kinase (BTK) Inhibitor

INDICATIONS FOR USE

- Pirtobrutinib has not yet been FDA approved for the treatment of CLL or SLL. However, it has received FDA approval for the treatment of CLL and SLL in some ways a similar BTK inhibitor to CLL and SLL. Once a drug has been approved for another indication, it can then be prescribed "off-label" by healthcare providers at their discretion. However, it is important to note that insurance plans may not cover the cost of medications that are prescribed off-label.
- Changing clinical trials for CLL and SLL have already shown that pirtobrutinib is effective in treating CLL and SLL, and the drug has been extensively well-tolerated. It is anticipated that pirtobrutinib will receive FDA approval for CLL and/or SLL in the near future.
- Pirtobrutinib can be used even when the CLL or SLL has developed resistance to covalent BTK inhibitors.

ADMINISTRATION ROUTE
 Taken orally by mouth (in tablet form).

LENGTH OF TIME ADMINISTERED
 Taken indefinitely until either the disease progresses while on the medication (which would require switching to a new class of medication to treat the CLL or SLL) or until certain unacceptable side effects occur requiring discontinuation of the drug.

DOING
 200 mg taken once per day, at the same time each day.

MISSED DOSE
 If you miss a dose of this medication, take it on the same day as soon as you remember as long as you are within 12 hours from the time when you regularly take this medication.

HOW TO TAKE THIS MEDICATION

- Swallow whole with water. Do not cut, crush, or chew the tablets.
- Do not ingest any start-up, grapefruit, bitter orange, or pomelo products.

COMBINATION THERAPIES
 No combination therapies are yet recommended.

COMMON SIDE EFFECTS
 Side effects can occur because of any medication, some of which may go away with time as your body adjusts to the new medication. Please notify your healthcare provider right away if any of the following side effects occur:

- Low neutrophil count, low white blood cell count, or low platelet count
- Shortness of breath
- Fatigue
- Muscle, joint, or bone pain
- Blushing or bleeding
- Diarrhea
- Swelling

Side effects not mentioned above may also occur. Notify your healthcare provider of any other unusual symptoms, as they may be able to help you adjust ways to prevent or reduce certain side effects.

MANAGING COMMON SIDE EFFECTS
 Some side effects are more common than others, many of which will go away after a short period of time after starting on the medication. It is important to talk to your healthcare provider to discuss if you might be able to manage side effects in the short term in order to stay on the therapy until your body has time to adjust to the new medication. Here are some possible ways to help manage some of the most common side effects of pirtobrutinib in combination with your healthcare provider.



When I was first diagnosed with CLL in 2020, the search for reliable information and assistance was daunting. The CLL Society quickly became my most valued and trusted source for all things CLL. I have recommended it to all newly diagnosed fellow CLL Warriors since then. Thank you for being here for us!

- Douglas Poad

Living with CLL since 2020, North Carolina

CAR-T AMBASSADOR PROGRAM

Cellular therapies like CAR-T (chimeric antigen receptor - T cell) are becoming an increasingly important option for individuals with CLL who require multiple lines of therapy. CAR-T is a complex treatment, and CLL Society acknowledges the value of peer-to-peer dialogue in aiding those considering this option. Through CLL Society's CAR-T Ambassador Program, individuals are connected to a fellow CLL patient who has received CAR-T therapy who will provide honest answers to candid questions and help determine if CAR-T is the right next step.



**COMPLETE A
COMMUNITY
PROFILE
WITH CLL SOCIETY
HELP US BETTER UNDERSTAND
THE PEOPLE WE SERVE**



COMMUNITY PROFILE QUESTIONNAIRE

To make meaningful progress for a community, it is crucial to first understand their situation and experiences. In the Fall of 2023, CLL Society launched our Community Profile Questionnaire to gain a deeper knowledge of the demographics and circumstances of individuals with CLL in our community, specifically related to the care they receive for their CLL. Knowing how people are managing their disease enables us to tailor our services to better fit the needs of our community. By the end of 2023, 580 individuals had completed the survey, providing invaluable insight into their lives.



SUPPORT FOR VETERANS WITH CLL

Some US military Veterans are at an increased risk for developing CLL/SLL due to environmental exposures that occurred during their service. These individuals qualify for healthcare through the Veterans Affairs (VA) system, separate from the general non-military population, making information on accessing care through this system very specific.

At CLL Society, we have a notable subset of our CLL patients who are also Veterans. Ensuring this group is informed of the care available to them and the unique process for accessing it are priorities for us. To accomplish this, CLL Society launched a Veterans with CLL/SLL section on our website, which includes an FAQ that guides Veterans on navigating access to care and benefits in the VA healthcare system.



Starting in 2023, we also began the process of creating a CLL Society Support Group specific to Veterans and their family members as a dedicated place where Veterans could commiserate on their shared experiences. The first official meeting took place in early 2024 with 105 individuals signed up.



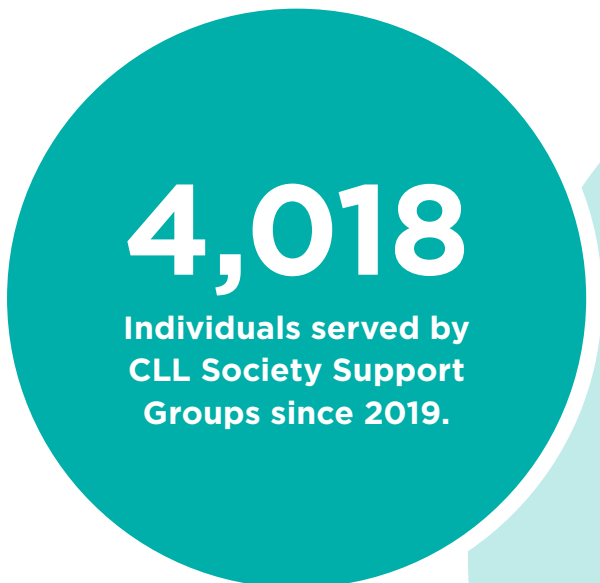


FOUNDATIONAL CLL SOCIETY SUPPORT AND EDUCATION PROGRAMS

Educational Events

Virtual educational presentations guided by expert healthcare providers discussing a wide range of topics important to living with and treating CLL, additionally recorded for later viewing.

In 2023, CLL Society hosted our first X Spaces events targeted towards educating the healthcare community on treating CLL patients. X Spaces were held following the ASCO and ASH 2023 conferences.



76%
of Expert Access™
participants stated that
they would make a change
or take follow-up
action after their
consultation.

Expert Access™

A free 30-minute consultation with an expert physician who has dedicated their practice to treating CLL. This program is available to any CLL patient seeking a second opinion on their treatment plan.



My Expert Access consultation was the best 30 minutes I've spent since being diagnosed, and I would encourage anyone at any CLL stage or treatment level to take advantage of this resource, no matter how excellent your local medical team is.

- Jan Jackson

Living with CLL since 2023, California

Ask the Experts

An email-based service where patients and care partners can submit questions and receive personalized answers from a healthcare professional knowledgeable about CLL, along with a library of archived responses.

1,000+
Patient and care
partner questions
answered.

76

Interviews with expert
healthcare providers
on the treatment and
management of CLL.

Patient and Care Partner Education

Easy-to-understand summaries accompanied by video interviews with healthcare professionals on the latest medical news and clinical trial updates in CLL, derived from presentations at major conferences and publications in prestigious medical journals.



A large, semi-circular graphic on the left side of the page. It features a white outer ring and a dark blue inner area that shows a microscopic view of a cell, possibly a lymphocyte, with visible internal structures.

CONNECTING SCIENTISTS TO FUNDING FOR ADVANCING TREATMENT DISCOVERIES

CLL Society's Research Program funds groundbreaking research and supports scientists dedicated to improving treatment options for CLL and SLL.

THE CLL SOCIETY RESEARCH PROGRAM

We are steadfast in our commitment to advance treatment options for CLL by funding innovative research projects and nurturing the development of young scientists poised to solve persistent challenges of this disease. CLL Society is the only nonprofit organization in the United States that is dedicated exclusively to funding research for CLL and SLL. Through 2023, our focus remained on funding research in the following four areas of critical unmet need:



- 1 Disease progression after receiving both a BTK inhibitor and BCL-2 inhibitor (double refractory disease)**
- 2 Richter's transformation**
- 3 Strengthening or reconstituting the impaired immune system**
- 4 Curative therapies**

We believe that supplying substantive grants to scientists devoted to CLL will lead to the discovery of novel approaches to improve patient outcomes.



CLL Society gives all CLL patients a 'home' where they can belong, where they are listened to, and where there is a wealth of information and support. CLL Society often says, "Stay strong - we are all in this together," and I find the notion of "together" to be powerful.

- Jeanne Henderson

Living with CLL since 2006, Georgia

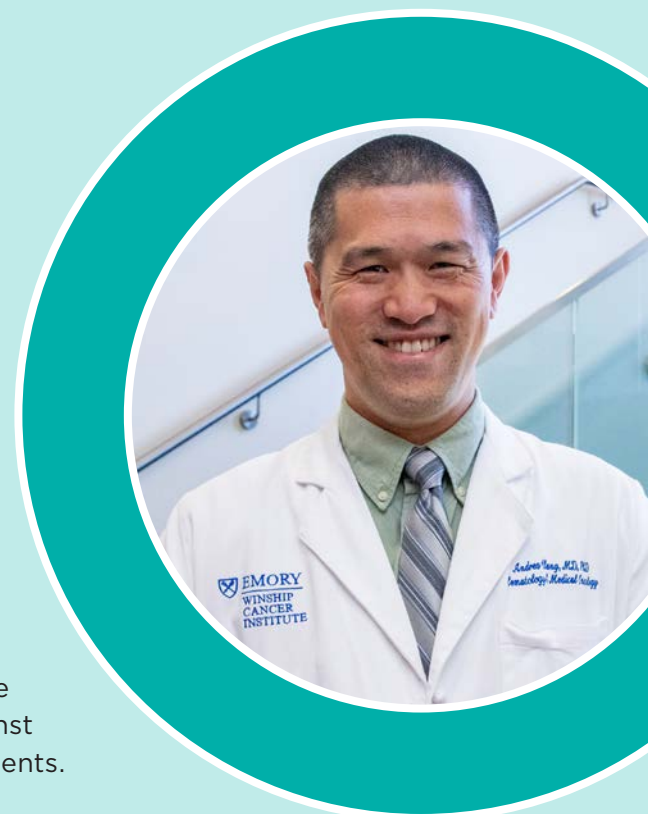
2023 Young Investigator Award

In July 2023, Dr. Andres Chang was granted the 2023 Young Investigator Award. This award supports a junior faculty member or postdoctoral fellow early in their career, focused on pre-clinical research. By providing meaningful financial support, we hope to empower researchers to establish themselves in CLL/SLL research.

Andres Chang, MD, PhD

Winship Cancer Institute of Emory University, Atlanta, GA

Dr. Chang's research project aims to understand how the immune system of individuals with CLL responds to vaccination. The study's findings will generate insights into enhancing protection against infections for these patients.



Expanding the Awards Offered for 2024

Applications for the 2024 award cycle were launched in September 2023, inclusive of two new funding opportunities alongside a third Young Investigator Award. With a growing funding capacity, our Research Program is well situated to amplify its impact in the years to come. We are exceptionally grateful for our numerous donors, whose generous contributions and belief in our mission are imperative to achieving these monumental strides towards advancing patient outcomes.

Integrative Medicine Award

The Integrative Medicine Award will focus on promoting early exploration of integrative approaches to tackling health challenges faced by those living with CLL/SLL. It also aims to contribute to the growing scientific evidence that incorporating integrative medicine practices into conventional cancer treatment plans can improve overall patient well-being.

The inclusion of the Integrative Medicine Award for the 2024 funding cycle was made possible by a matching grant from Vigyan Singhal and the Sim Einstein Research Foundation, Inc. with additional contributions from our community.

Clinical Scholar Award

This award is dedicated to funding a physician researcher who has an established career in studying CLL/SLL. Research funded through this award intends to contribute to progress in the treatment or prevention of CLL while also continuing to support the career of the physician-scientist.





FORMING TIES TO FIGHT FOR HEALTH EQUITY

Through our Equitable Community Care Outreach Initiative and Policy Institute, CLL Society aims to address health inequities in CLL/SLL treatment and expand our services into the communities we are not yet reaching.

EQUITABLE COMMUNITY CARE OUTREACH (ECCO) INITIATIVE

Health inequities persist in what treatment options are presented to individuals living with CLL/SLL, largely influenced by patients' geographic location and their access to CLL experts. In response, CLL Society is committed to expanding our services into the community and connecting with the approximately 80% of CLL patients who receive care in this setting. While our efforts have historically focused on major academic centers, we are now aiming to reach traditionally underserved patient populations through diversifying our outreach strategies and implementing targeted initiatives that reflect our work at the community level.

It is our strong belief that when patients are equipped with education and resources about their disease, they are more likely to take responsibility in their care. They are better positioned to advocate for receiving appropriate testing and seek out innovative therapies that are proven to yield better outcomes. Without this knowledge, many individuals in the community settings continue to be unaware they are receiving suboptimal treatment.

CLL SOCIETY Resource Library

CHRONIC LYMPHOCYTIC LEUKEMIA

WHAT IS CHRONIC LYMPHOCYTIC LEUKEMIA?

Chronic lymphocytic leukemia (CLL) is a slow-growing blood cancer involving the abnormal overgrowth of a type of white blood cell called B-lymphocytes. In CLL, not only are too many abnormal B-lymphocytes produced, but the cancerous cells also live longer than healthy B-lymphocytes do. With time, these cancerous B-lymphocyte cells accumulate in the blood, bone marrow, lymph nodes, and spleen. CLL is also classified as a type of non-Hodgkin's lymphoma. Although CLL is the most common adult leukemia in North America, it is considered a rare cancer with only 21,000 cases diagnosed annually.

WHAT CAUSES CHRONIC LYMPHOCYTIC LEUKEMIA?

The exact cause of CLL is still unknown. As with many types of cancer, advancing age plays a significant role. Researchers are continually working to understand the exact mechanisms that cause the disease. While many suspect the cause might be related to genetic mutations occurring in the DNA, specific genes that cause CLL have not yet been identified. The disease typically occurs spontaneously. CLL is generally not considered hereditary in the sense that it cannot be directly passed down to children. However, some new research suggests that in rare cases there may be a connection to a family history of blood cancers.

WHAT ARE SOME OF THE RISK FACTORS FOR DEVELOPING CHRONIC LYMPHOCYTIC LEUKEMIA?

- **Age:** CLL is usually diagnosed in people that are over 60 years old, but it can occur in much younger adults. CLL is extremely rare in children. About 90% of people diagnosed are older than 50 years old, with the average age being 71 years old.
- **Gender:** Men are almost twice as likely to be diagnosed with CLL compared to women.
- **Race/Ethnicity:** CLL is more frequently affected in White individuals, followed by Hispanic and Native Americans. It is a higher disease associated with Ashkenazi Jewish descent.
- **Environmental, Occupational, and Exposure:** People exposed to pesticides and toxins seem to be at an increased risk for CLL. For example, living near a farm has been associated with an increased risk of CLL. Factors such as pesticide use, radon exposure in homes may also increase the risk of developing CLL.
- **Veterans:** The U.S. Department of Veterans Affairs lists CLL as a disease associated with exposure to Agent Orange, a chemical used during the Vietnam War. An increased risk has also been associated with exposure to burn pits in the war with Iraq.

HOW IS CHRONIC LYMPHOCYTIC LEUKEMIA DIAGNOSED?

Usually, after a routine complete blood count (CBC) shows an elevated absolute lymphocyte count (ALC), a special test called flow cytometry is done (using either a sample of blood or bone marrow) to confirm that the cause of the high ALC is due to CLL. Flow cytometry looks for specific markers (such as CD20) on the surface of the cancerous cells. The diagnosis of CLL requires a finding of more than 5 x 10⁹/L genetically identical (clonal) CLL cells through flow cytometry.

WHAT ARE THE SYMPTOMS OF CHRONIC LYMPHOCYTIC LEUKEMIA?

CLL is often diagnosed incidentally during a routine blood test. Common symptoms include:

- Fatigue
- Night sweats
- Weight loss
- Frequent infections
- Enlarged lymph nodes
- Anemia (tiredness, weakness)
- Bleeding or bruising easily
- Bone pain
- Abdominal swelling (due to enlarged spleen or liver)

CLL SOCIETY Resource Library

CANCER-RELATED FATIGUE

WHAT IS CANCER-RELATED FATIGUE?

Fatigue is one of the most common symptoms experienced by those living with chronic lymphocytic leukemia (CLL) and small lymphocytic lymphoma (SLL), and it is also commonly overlooked, underreported, and undertreated. This may be due to a lack of awareness that fatigue does not have to be a normal part of having cancer, and that it can be treated. Those who experience cancer-related fatigue feel exhausted to the point of not being able to perform normal activities throughout the day, and often the fatigue does not improve with additional sleep or rest.

WHAT ARE THE DIFFERENCES BETWEEN CANCER-RELATED FATIGUE AND TIREDNESS?

Even those without cancer experience periods of tiredness. But feeling tired should not last for very long, and it should drastically improve after getting additional rest. Cancer-related fatigue is not the same as tiredness. With cancer-related fatigue, there is a feeling of intense weakness and an overall lack of energy to perform normal activities. One of the main differences is that getting additional rest or sleep may not improve symptoms. Arms and legs may feel heavy or difficult to move, and the exhaustion may be so extreme that there is no desire to eat or walk to the bathroom even after resting or sleeping for long periods of time.

WHAT CAUSES CANCER-RELATED FATIGUE?

Cancer-related fatigue is not fully understood, but here are some possible causes:

- The cancer itself (especially when the cancer is progressing)
- Cancer treatments (and the fatigue may linger even after the medication is no longer being taken)
- Emotional factors (depression, stress, and anxiety)
- Significant anemia, including autoimmune hemolytic anemia
- Chronic diseases including diabetes, heart disease, and conditions affecting the thyroid, kidney, and liver
- Vitamin and mineral deficiencies (iron, vitamin D, and vitamin B12)
- Dehydration
- Poor nutrition or not eating enough calories
- Chronic pain
- Drugs used to treat other symptoms and medical conditions
- Insomnia or sleep apnea

ARE THERE ANY NON-MEDICAL STRATEGIES THAT CAN HELP IMPROVE CANCER-RELATED FATIGUE?

There are several strategies that may improve cancer-related fatigue:

- **Exercise:** Focus on light activities and movement like stretching and walking, even when it seems counterintuitive due to a lack of energy. Avoid exercise late in the evening. Exercise has been shown to boost energy levels and improve cancer-related fatigue.
- **Nutrition:** Not getting enough calories can deplete energy reserves, so it is important to eat a balanced, healthy diet (with plenty of grains, fruits, vegetables, healthy fats, and protein).
- **Hydration:** Stay well-hydrated by drinking at least 64 ounces of water per day and limit caffeinated beverages.
- **Conserve Your Energy:** It is important to take short rest breaks throughout the day and pace yourself. Keep a written fatigue log so you can easily identify what times of the day you seem to have the most energy.
- **Sleep Hygiene Habits:** Go to bed at the same time every day and do your best to get 7-8 hours of uninterrupted sleep each night. If you nap during the day, limit it to one 20-minute nap, as sleeping too much throughout the day can impact how well you sleep at night. Keep the bedroom temperature cool, make sure it is without noise distractions, consider using blackout curtains to keep the room dark, avoid electronics before falling asleep, and try to relax before bedtime by listening to soft music or reading a book.
- **Pace Your Daily Activities:** Decide which daily activities are the most important to do, then set small goals throughout the day to complete them.

CLL SOCIETY
www.CLLSociety.org

Building a Library of Plain-Language Educational Resources

Chronic lymphocytic leukemia is a complex and chronic cancer that remains uncured. In 2023, we began building a library of informational resources that community-based healthcare professionals can provide to their patients.

Throughout 2023, CLL Society developed 23 informational handouts written in straightforward language covering various essential CLL topics. Also included in this library are the nine handouts from our CLL Medicine Cabinet detailing approved CLL medications.

Exhibiting at Local and Regional Hematology Conferences

To engage healthcare providers in the communities where most CLL patients are treated, CLL Society began exhibiting at various regional hematology and oncology conferences. At these conferences, we share packets of our new CLL informational handouts, CLL Medicine Cabinet sheets, and details about our patient support programs with healthcare providers from across the country. These resources not only inform providers themselves but are also intended to be passed along to patients, enabling them to learn about their disease and connect with CLL Society.

In 2023, we exhibited live at seven hematology/oncology conferences and virtually at another four. Through these exhibits, CLL Society engaged with over 900 healthcare providers.

Through this effort, we are seeking to enhance quality care and patient outcomes nationwide, so that no matter where a patient resides, they can access the best treatments.

Moreover, we are reaching out to patients who are not yet connected to us, offering them a proactive way to learn about their disease and find support.



I was recently diagnosed with CLL and CLL Society has been instrumental in understanding and receiving excellent care.

- Kristine O'Reilly

Living with CLL since 2021, Minnesota



ADVOCATING FOR ACCESSIBLE AND QUALITY CARE

In 2023, CLL Society galvanized our commitment to advocating for policy changes that will benefit those living with CLL and SLL through the formation of the CLL Society Policy Institute and PIRC, a coalition of stakeholders in the rare cancer community. We worked behind the scenes on outreach to key government officials and agencies to make patient voices known and direct change on key legislative initiatives. Priorities were organized under three pillars:

- **Access:** Ensuring equitable access to quality and affordable care
- **Innovation:** Protecting and improving pathways to development of new treatments
- **Needs of the Immunocompromised:** Ensuring our specific needs are not forgotten by decision makers



The CLL Society Policy Institute

The CLL Society Policy Institute, guided by our three pillars, made over a dozen formal appeals to the FDA, Centers for Medicare and Medicaid Services (CMS), and CDC throughout 2023 on issues of importance, including but not limited to:

- **Consideration of immunocompromised patients in relation to COVID-19 recommendations**
- **Raising awareness of immunity-related challenges**
- **The need for clear communications and careful implementation in the rollout of key Inflation Reduction Act (IRA) provisions**
- **Calling for transparency on issues that impact patients**
- **Urging preservation of accelerated approval pathways**
- **Providing opinions on clinical outcome assessments and endpoints**
- **Increasing inclusion of underrepresented populations in clinical trials**
- **Supporting caps on out-of-pocket prescription costs**



Protecting Innovation in Rare Cancers (PIRC) Coalition

Recognizing the need for a collective voice to represent the broader rare cancer community, particularly as the IRA introduced changes to the healthcare system that would have an outsized impact on these patient groups, CLL Society spearheaded the creation of the Protecting Innovation in Rare Cancers (PIRC) Coalition. PIRC is a collaborative, multi-stakeholder, patient advocacy group that has worked tirelessly to safeguard access to innovative treatments for patients and families affected by rare cancers.

In 2023, PIRC authored multiple letters to CMS, and participated in the CMS Listening Sessions, where three members of the CLL Society staff were selected to speak. Dozens of advocacy groups from around the nation have joined CLL Society, giving our messages strength in numbers.





CELEBRATING LONG LIVES

MAY 13, 2023



BUILDING RELATIONSHIPS THROUGH PHILANTHROPY

It is due to the continuous generosity of our community that we can enhance our programs and support innovative research, improving the lives of those affected by CLL/SLL. CLL Society offer various way for individuals to contribute, including donations, legacy gifts, and hosting or participating in fundraisers.

CELEBRATING LONG LIVES 5K WALK & RUN

CLL Society's second annual Celebrating Long Lives 5K took place virtually on May 13, 2023. This event is the largest connector for our patients, care partners, and loved ones around the country annually, offering a unique time to support and raise awareness of those who have been impacted by chronic lymphocytic leukemia or small lymphocytic lymphoma.

Again this year, we saw individuals empowered to tell their stories and uplift each other along their shared journeys.

We were honored to witness many members in our community take an active fundraising role, raising \$56,293 to fuel the mission of CLL Society.



2023 Participants

In Fort Wayne, Indiana, a cheerful group participated in the 2023 5K event. Among them, two individuals are living with CLL, and the rest came out to show their support for them and the broader CLL community.

Group organizer Sara Nordling shared, "A lot of times you can feel so alone in this. Great to share the love today and raise money for a good cause!"

Top Fundraisers

Neil Muchin: \$5,104 raised
Raye Murphy: \$3,105 raised
Harry Murley: \$2,000 raised

Top Teams

Team BeiGene: \$4,841 raised
CLL Sunshine Sisters and Brothers: \$2,502 raised
Western North Carolina CLL Support Group: \$2,088 raised





“ ”

I ran my 5K with my running club. I'm happy to Celebrate Long Lives with the CLL Society because I've appreciated their support over the past two and a half years.

- Jennifer Albright

*Living with CLL since 2020
California*

“ ”

My CLL 5K was a walk to visit most of the art studios in the Gateway Arts District Open Studios, Maryland. A friend went with me, and we had a great time. I'm so grateful to CLL Society for being the go-to place when I was diagnosed in 2021 and for hosting the DC Area CLL Support Group. I'm so thankful to have resources and support along this journey.

- Lauren Rauk

*Living with CLL since 2021
Maryland*



“ ”

Beyond grateful for the CLL Society and for the opportunity to clock some steps today for this amazing resource.

- Holly Watson-Evans

*Living with CLL since 2020
Illinois*



GIVING TUESDAY

Giving Tuesday

Our community never ceases to amaze us during our Giving Tuesday campaign, contributing \$113,284 in 2023 to help those impacted by CLL. Our sincerest thanks to each person who joined us. When we see this level of generosity, it is overwhelmingly clear that the programs and education we provide are essential.



We are grateful for the work of all those in the CLL Society who unscramble the volume of new data that surrounds us and turn it into information.

- True Ryndes and Jim Anderson

Living with CLL since 2010
(True); Care Partner (Jim)
California



CLL Society has given me so much information and support that it's difficult to imagine navigating this disease without this help.

- Jo Ann Weber

Living with CLL since 2019
Michigan



I was diagnosed with CLL/SLL in 2007 and have relapsed three times. Thankfully, my current treatment of ibrutinib is keeping me in remission. For many years, the CLL Society has provided me with invaluable information and support through the journey, and they have become my go-to resource for advice, research, and education. I know I'll always get straight answers from them. Thank you for what you do!

- Anonymous

A Donor's Story



I am making this donation to the CLL Society because I have personally experienced the challenges and impact of living with CLL. This donation is my way of expressing gratitude for the support and resources provided by the CLL Society throughout my journey.

I am inspired by the dedication of the CLL Society in raising awareness, advancing research, and providing educational programs for patients like me. By making this donation, I hope to contribute to the CLL Society's mission of improving the lives of CLL patients and their families.

Thank you for all that you do!

- Terri Edwards

*Living with CLL since 2015
Florida*





MESSAGE FROM THE DEVELOPMENT DIRECTOR

A note to our wonderful supporters,

Thanks to the generosity of our CLL Community, 2023 was a record-breaking year for our fundraising program. This is important because so much of what CLL Society does is made possible by support from individuals who are personally affected by this disease, as patients, care partners, family members or friends.

At CLL Society, we know that Smart Patients Get Smart Care™. As long as there are people living with this disease, we will be here providing vital education and resources, funding new research, and doing all we can to improve and extend lives.

CLL Society is the only organization dedicated to serving the CLL/SLL Community exclusively – improving care for all living with CLL/SLL is our sole reason for existing. So, when you make a donation to this organization, you know that you are directly supporting the programs and educational resources that will benefit the CLL/SLL Community. Many great organizations are working to help people with all kinds of cancer, but none have this laser focus on CLL/SLL that CLL Society does.

There are a number of ways in which you can have a meaningful impact on the work of CLL Society. You can always make a cash or monthly recurring contribution safely and easily on our website, but here are a few other important ways you may be able to help:

- **Leave a Legacy** – Name CLL Society in your will or trust, or make the organization a beneficiary of your life insurance or retirement plan. It’s easier than you think and allows you to provide for yourself and family first.
- **If you own appreciated stock**, consider donating shares directly to CLL Society and avoiding a tax burden.
- **Do you have annual required minimum distributions (RMDs) from an IRA?** You may be able to donate all or part of this directly to CLL Society and pay no taxes on the donated amount. This is called a qualified charitable distribution, and if you are 70 ½ years or older you can give any amount up to \$100,000 annually.
- **Make a donation in honor of someone who has helped you on your CLL journey** – a family care partner, doctor, nurse – and we will send them a note letting them know how much their care means to you.
- **Check to see if your employer (or former employer, if you are retired) has a matching gift program.** Many do, and they can make it easy to double the impact of your gift.
- **Host a fundraiser** – Do something fun in your community with friends and family and make it a fun-raiser and a fund-raiser!

If you would like more information about any of these opportunities, please contact Ron Katz, CLL Society’s Development Director, at rkatz@cclsociety.org, or call (860) 575-2605. Together, we can figure out which giving option is best for you.

Thank you for making a difference!



A handwritten signature in black ink that reads "Ron Katz".

Ron Katz
Development Director



My father has CLL, so I make an annual donation and my company matches it. This is a cause that is tremendously important to me and my family.

- Anonymous donor







FINANCIALS

INDUSTRY PARTNERS

CLL Society is grateful for our continued partnerships with numerous industry members committed to making lifesaving education and support accessible to CLL/SLL patients and their care partners.

2023 Industry Advisory Council

The Industry Advisory Council (IAC) is comprised of companies committed to advancing initiatives for the CLL community. We appreciate the support of the following 2023 IAC Members.

Platinum Members



Gold Members



Silver Members



Additional Supporters

- | | | |
|-------------|-------------------|------------------|
| AbbVie | BMS | Lilly |
| Adaptive | Grifols | Offscrip Media |
| Ascentage | Genentech | PlatformQ Health |
| AstraZeneca | Invivyd | Pfizer |
| BeiGene | Lava Therapeutics | Secura Bio |

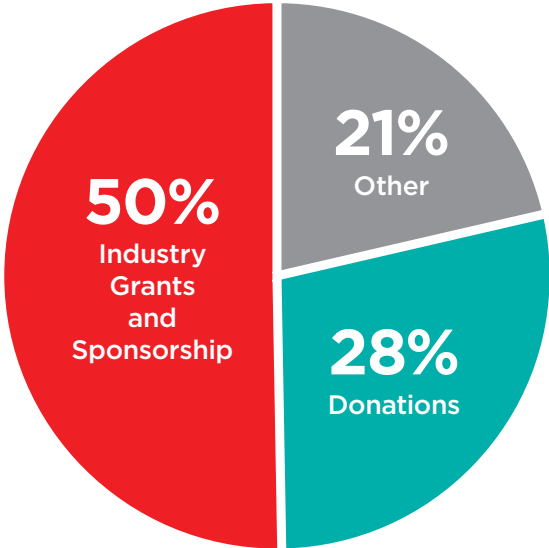
Special Thanks to Our Health Equity Sponsors

CLL Society is grateful to **AstraZeneca** and **Lilly** for their partnership in our health equity efforts to advocate for equitable access to quality care for all those living with CLL/SLL.

2023 FINANCIALS

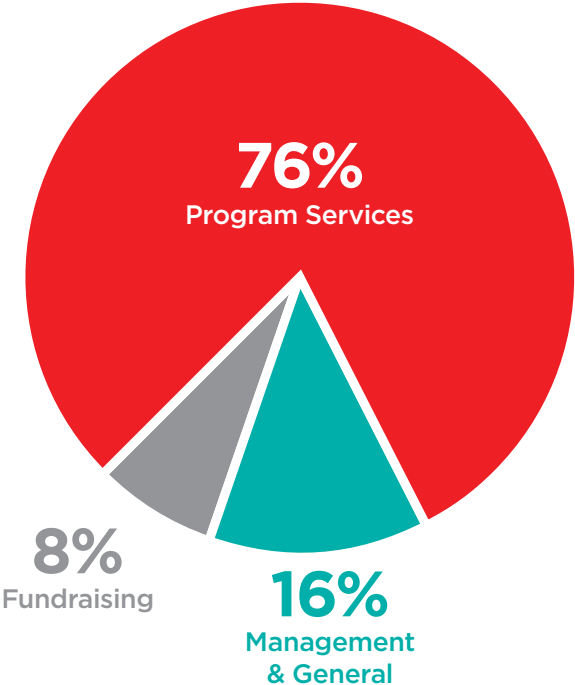
Revenue

Industry Grants and Sponsorship	\$1,474,417	50%
Donations	\$822,960	28%
Other	\$627,003	21%
TOTAL	\$2,924,380	



Expenses

Program Services	\$2,042,916	76%
Management & General	\$429,434	16%
Fundraising	\$209,847	8%
TOTAL	\$2,682,197	







**THANKS TO
OUR DONORS**

DONOR ACKNOWLEDGMENTS

CLL Society is incredibly grateful for the dedication of individuals, foundations, and corporations who continue to support our work year after year. We would not be able to provide CLL and SLL patients, care partners, and healthcare professionals with the support and education we do without you. Thank you.

Acknowledged below are the individuals who donated \$500 or more in 2023.* Beyond the names listed below, we received numerous donations of less than \$500, while others donated more but wished to remain anonymous. We are extremely grateful for every donation, regardless of the amount.



\$100,000+

1 Anonymous Donor

Robert Duggan

\$20,000–\$99,999

2 Anonymous Donors

Sim Einstein Research Foundation, Inc. (SERFI)

\$10,000–\$19,999

3 Anonymous Donors

Douglas A. Himes

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16 Anonymous Donors

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\$1,000–\$4,999 (Continued)

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Martha Nathanson	
Rebecca Newton	

\$500–\$999

9 Anonymous Donors	Victoria Bour
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Deborah Ayers	Raymond G. Burton
Joel Bacon	David Byron-Brown
Robert A. Barton	Adriene Cardan

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CLL SOCIETY

**Smart Patients
Get
Smart Care™**



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the work of CLL Society
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