# SUPPORT THAT EMPOWERS

# 2024

## ANNUAL REPORT

CLL SOCIETY

# SUPPORT THAT EMPOWERS

Chronic lymphocytic leukemia (CLL) is a complex disease, with a journey that can span from diagnosis and active observation (watch and wait) to treatment, relapse, and long-term survivorship. CLL Society is dedicated to empowering individuals with CLL or small lymphocytic lymphoma (SLL), along with their care partners and loved ones, by providing compassionate support that enables them to make informed decisions and navigate their journey with confidence.

In 2024, our focus was on delivering support that empowers through personalized connections, purposeful educational resources, and groundbreaking research, always with the goal of improving the quality and longevity of the lives of those living with CLL.

Supporting and empowering the CLL/SLL community is at the heart of our mission. As we continue to expand CLL Society's services and impact, we are steadfast in our commitment to empower those living with CLL at every stage of their journey.

## Our Vision

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.

## Our Mission

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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# EXECUTIVE STATEMENT

CLL Society continually strives to create a world where everyone impacted by CLL/SLL has access to trusted education, compassionate support, and expert-informed care — so they can live longer, stronger, and more fulfilling lives. This is more than a vision. It's our commitment. And in 2024, we took bold steps to bring it to life.

The theme of this year's annual report is "Support That Empowers" because we believe that empowerment is the key to living longer, healthier lives with CLL. Whether newly diagnosed, navigating a relapse, or caring for a loved one, our goal is to ensure no one is left to figure it out alone. The right support doesn't just comfort—it equips. It informs. It strengthens.

## Throughout 2024, we delivered on this promise in powerful ways.

- Our educational events reached over 2,800 individuals
- Our support groups added nearly 750 new participants
- New 1-on-1 Peer Support programs offer additional personalized support
- Over $1 million in additional research grants were awarded to advance our scientific knowledge specifically in CLL and SLL

These are just a few ways that we continued to increase our impact throughout 2024.

However, we know that roughly 80% of CLL patients in the U.S. are treated in community settings, often without the benefit of CLL-specific expertise. That's why we doubled down on our Equitable Community Care Outreach (ECCO) initiative. In its second year, ECCO became a force for change, bringing CLL-specific education, resources, and connection directly to the people and places where it's needed most.

In 2024, ECCO embedded expert-reviewed, empowering materials directly into community oncology practices across the country, and fostered stronger connections with non-specialist providers, helping them make more informed decisions for their patients. The impact? Thousands of patients who once felt isolated or underserved now have the tools and information they need to take charge of their care.

## What else happened in 2024 at CLL Society?

We launched enhanced digital tools and redesigned key parts of our website to make expert information easier to find and understand;

We added new peer support groups, creating safe spaces for meaningful connection, shared experience, and emotional resilience;

Through our advocacy efforts, we fought to protect access to treatments, reduce out-of-pocket costs, and preserve innovation pipelines;

We expanded our research program to include support for important work in integrative medicine, focusing on ways to improve the physical and emotional quality of life for everyone living with CLL.

Every step of the way, Support that Empowers remained at the core of our mission. Support that is compassionate. Support that transforms confusion into clarity. Support that reduces isolation and gives us the power to make informed decisions.

Thank you for walking alongside us this year. Together, we are creating a future where everyone impacted by CLL/SLL has the knowledge, tools, and support they need to thrive.

**Stay strong. We are all in this together.**

**Brian Koffman, MDCM**
*Co-Founder*

**Carly Harrington, MEd, MBA**
*Executive Director*

**Steve Bloom**
*President & Chair*

# CLL SOCIETY LEADERSHIP

## Board of Directors

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*Secretary*

**John Backus**
*Treasurer*

**Brian Koffman, MDCM (retired), MSEd**
*Member at Large*

**Robert Levis***

**Susan O'Brien, MD**

**David Stern**

**Kirk Taylor, MD**

## CLL Society Staff

**Brian Koffman, MDCM (retired), MSEd**
*Chief Medical Officer, Executive Vice President, Co-Founder*

**Carly Harrington, MEd, MBA**
*Executive Director*

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*Senior Director of Scientific Affairs and Research*

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*Program Director*

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*Development Director*

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**Nicole Kamphuis, MPA**
*Development and Communications Manager*

**Fernando Parra Chong**
*Strategic Partnerships Manager*

**Vickie Miller***
*Patient Education Manager*

**Nancy Day**
*Program Coordinator*

**Sarah Castro**
*Administrative Coordinator, Scientific Affairs & Research*

**Albie Suozzi**
*Content Coordinator*

**Frances Reilly**
*Business Support Administrator*

**Saira Sultan, JD**
*Director of Government Affairs & Public Policy*

*Departed in 2024.

# Medical Advisory Board

**Alexey Danilov, MD, PhD, *Chair***
*City of Hope*

**Matthew S. Davids, MD, *Co-Chair***
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**Ryan Jacobs, MD**
*Atrium Health Levine Cancer Institute*

**Nitin Jain, MD**
*MD Anderson Cancer Center*

**Adam Kittai, MD**
*Mount Sinai*

**Nicole Lamanna, MD**
*Columbia University Medical College*

**Onyemaechi Okolo-Taku, MD**
*Ironwood Cancer & Research Centers*

**Javier Pinilla-Ibarz, MD, PhD**
*H. Lee Moffitt Cancer Center and Research*

**Alan Skarbnik, MD***
*Novant Health*

**Deborah Stephens, DO***
*Lineberger Cancer Center at the University of North Carolina*

**Jennifer Woyach, MD**
*The Ohio State University Comprehensive Cancer Center - James*

**Laura Zitella, MS, RN, ACNP-BC, AOCN**
*University of California San Francisco*

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*Patient*

**Elizabeth Dechen**
*Patient*

**Terry Evans**
*Patient*

**Stephen Feldman**
*Patient*

**Jo-el Fernandez**
*Care Partner*

**Lexii Freitas**
*Patient*

**Sonja Hampton**
*Patient*

**Julianne Jones**
*Patient*

**Larry Marion**
*Patient*

**Barbara Massey**
*Patient*

**Howard Massey**
*Care Partner*

**Raye Murphy**
*Patient*

**Dan Patterson**
*Patient*

**Christina Rodriguez Fuller**
*Patient*

**Haleh Simi**
*Patient*

**Albie Suozzi**
*Patient*

**Michael Turner**
*Patient*

**Doreen Zetterlund**
*Patient*

# International Patient Advocates

**Michael Rynne**
*Care Partner*
Ireland

**Deborah Sims**
*Patient*
Australia

**Nick York**
*Patient*
United Kingdom

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**Departed in 2024.*

# 2024 IMPACT

**$918,825**

donated by individuals to advance the mission of CLL Society

**2,820+**

individuals empowered with knowledge through CLL Society education events

**742**

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

**2**

new 1-on-1 programs launched to support patients and care partners with the emotional impact of CLL/SLL and informed care decisions

**$1,050,00**

awarded to scientific research specifically in CLL since CLL Society's Research Program launched in 2022

**4**

research grants awarded in the 2024 funding cycle to advance scientific research specifically in CLL

**11**

media features that highlighted CLL Society as an expert voice on CLL-related matters

**2,430**

downloads of CareCast, CLL Society's podcast channel which launched in 2024

# EMPOWERING SUPPORT AND EDUCATION

In 2024, we explored new and impactful methods for delivering empowering support and education to those diagnosed with chronic lymphocytic leukemia (CLL) or small lymphocytic lymphoma (SLL). These efforts provided patients and care partners with the tools to confidently navigate their diagnosis, receive optimal care, and improve the quality and longevity of their lives.

We introduced two new programs offering personalized, 1-on-1 support for those living with CLL and their care partners. To strengthen our educational resources, we created expert-led, topic-specific videos and revitalized our Test Before Treat awareness campaign. Additionally, the *CareCast Podcast* debuted sharing real patient journeys.

# PEER SUPPORT PROGRAM

To better serve the diverse needs of our community, we introduced a new 1-on-1 Peer Support Program that connects individuals with others who are personally impacted by CLL. Sometimes, the most powerful advice comes from those who have already gone through a similar experience. These peer connections offer real-life insights, encouragement, and hope from someone who truly understands the journey, providing empowering support as individuals navigate life with CLL. This kind of support can be vital for strengthening mental and emotional well-being, helping people feel seen, understood, and less alone.

In 2024, **90 individuals** participated in the Peer Support Program, receiving compassionate, personalized support. Through these connections, participants gained knowledge about their disease and built the confidence to advocate for their health.

# EMOTIONAL AND SPIRITUAL ADVOCATE PROGRAM

The emotional impacts of living with or caring for a loved one with CLL can be profound. Receiving guidance from a professional can be incredibly reassuring and empowering during these challenging times. CLL Society's Emotional and Spiritual Advocate Program offers those in the CLL community the opportunity to meet with a board-certified chaplain for support. Regardless of one's faith, spiritual background, or lack thereof, individuals can receive personalized counsel on a wide range of matters they may be facing, including coping with the challenges of living with CLL, bereavement and grief, spirituality in a time of illness, care partner support, and more.

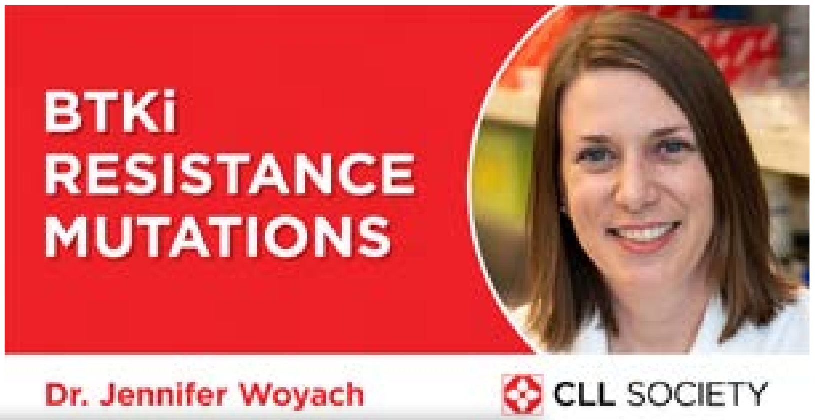
This additional service of 1-on-1 support amplifies CLL Society's dedication to meeting individuals where they are and providing tailored care that addresses their unique needs because we understand that everyone's journey is different. In 2024, **63 individuals** participated in our Emotional and Spiritual Advocates Program.

# LEARNING SPOTLIGHT VIDEOS

To add depth and variety to our virtual educational offerings, CLL Society began producing short, topic-specific videos featuring expert healthcare providers.

These videos deliver focused learning spotlights, diving deeper into key issues relevant to individuals living with CLL. The content is made more engaging by pairing each video with pre- and post-activity assessments, along with supplemental educational resources when applicable.

In 2024, we covered topics including treatment duration options, resistance to certain therapies, and more. New videos are added to our growing library of on-demand education, available anytime on CLL Society's website for patients and care partners seeking trusted, expert-guided information.



BTKi RESISTANCE MUTATIONS

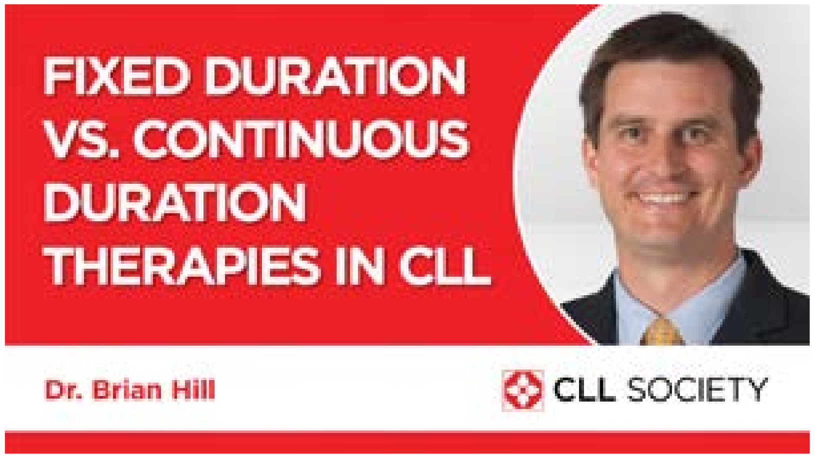
Dr. Jennifer Woyach

CLL SOCIETY

TIME OFF TREATMENT IN CLL

Dr. Catherine Coombs

CLL SOCIETY



FIXED DURATION VS. CONTINUOUS DURATION THERAPIES IN CLL

Dr. Brian Hill

CLL SOCIETY

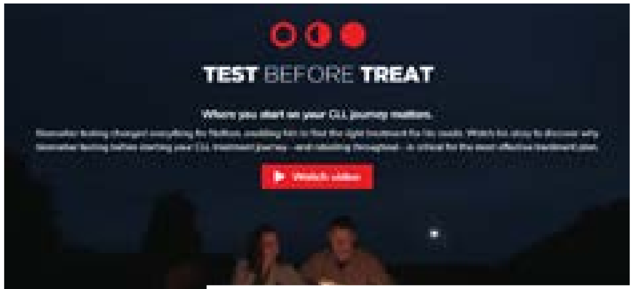
> *I was diagnosed with CLL a few months ago. I have been extremely impressed with the breadth of information provided by the CLL Society as well as the helpfulness of the support groups. It has made navigating the stressful first months of this diagnosis so much easier. Thank you so much!*
>
> ***- Holly D. Crumpler***
>
> ***CLL Patient since 2024, North Carolina***

# TEST BEFORE TREAT CAMPAIGN

CLL Society

**TEST**
BEFORE
**TREAT**

Powered by BeOne Medicines



TEST BEFORE TREAT

Where you start on your CLL journey matters.

Since its launch in 2017, Test Before Treat has been a flagship awareness campaign of CLL Society. Through this campaign, we educate individuals living with CLL about the critical importance of biomarker testing before beginning any treatment, and prior to each subsequent line of therapy. This testing helps ensure that every patient receives the treatment most likely to be effective for their unique disease. Central to our mission is seeing that patients with CLL receive the best care possible, and knowing one's biomarker status plays a key role in guiding treatment decisions.

In 2024, CLL Society, in partnership with BeOne Medicines (formerly BeiGene), expanded and revitalized the campaign, reaffirming our commitment to ensuring patients receive the most effective treatment personalized to their specific form of CLL. The reimagined campaign was unveiled at the American Society of Hematology (ASH) Annual Meeting and Exposition in San Diego, the largest gathering of hematology professionals in the United States.

At ASH, Test Before Treat was featured in both the CLL Society and BeOne booths, directly engaging healthcare providers on the essential role of biomarker testing in treatment decisions for CLL and SLL patients. To broaden our reach, we also redesigned the Test Before Treat webpage, streamlining access to crucial information and resources, with all campaign communications directing people to this central hub.

A powerful element of this campaign was the personal story of Nathan, a person living with CLL, who shares how biomarker testing led him to the right treatment path. His story serves as an inspiring and motivational call to action for others. Through this campaign, we continue to empower patients with the knowledge they need to make informed decisions and engage in shared decision-making with their healthcare teams to achieve the best possible outcomes.

https://cllsociety.org/newly-diagnosed/test-before-treat/

# CARECAST: THE CLL SOCIETY PODCAST

CARE CAST

THE CLL SOCIETY PODCAST

CLL affects each individual differently, and we recognize the importance of highlighting these unique experiences. To give voice to the diverse journeys of those living with CLL, we launched the podcast CareCast. Throughout the episodes, we cover the full spectrum of the CLL experience from diagnosis, to watch and wait, starting treatment, reaching long-term stability and survivorship, to potential relapse and starting over again.

Through candid conversations with patients and care partners, CareCast shares real-life stories that shed light on the emotional, physical, and practical realities of living with CLL. By offering diverse perspectives, the podcast fosters a sense of belonging and empowerment, helping individuals feel supported and less isolated.

> *This was an excellent webinar! I am a CLL patient and also a PhD research scientist and I find the CLL Society webinars and communications strike an excellent balance in presenting complex topics in a meaningful way for a broad audience without overdoing the 'dumbing down' of the subject. Thank you for the incredible service you provide to the CLL community.*
>
> ***- Alan McClelland***
>
> ***CLL patient***

> *Expert Access gave me peace of mind in making my decision to start treatment and deciding what treatment to choose. The virtual appointment put my anxiety to rest, and I have the summary of my visit to share with my oncologist. I feel much more confident going forward in the treatment of my CLL, and I am very thankful I was given the opportunity to speak with a CLL specialist.*
>
> ***- Ruth***
>
> ***CLL Patient since 2024, California***

# FOUNDATIONAL CLL SOCIETY PROGRAMS

## Educational Events

Our virtual educational events are guided by expert healthcare providers presenting on a wide range of topics and are recorded for later viewing. Our "Ask Me Anything" Facebook Live events feature both an expert healthcare provider and a CLL patient advocate, focusing entirely on answering audience questions. In 2024, we added written transcripts to our on-demand educational events to make this content more inclusive and accessible.

**10**

**Educational Events and**

**3**

**"Ask Me Anything" events with an average excellent/ good rating of**

**98%**

## 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.

**88%**

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

**100%**

**of Expert Access participants learned something new from their Expert Access physician**

## Support Groups

These facilitator-led support groups offer individuals the opportunity to share experiences, learn about their disease, and gain emotional support from empathetic peers in a structured environment.

**Veterans with CLL Support Group launched in 2024**

**4,779**

**Individuals served by CLL Society Support Groups since 2019**

## 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.

**293**

**patient and care partner questions answered**

# EMPOWERING RESEARCH

CLL Society's Research Program achieved a significant milestone in 2024 by awarding over $1 million in CLL-specific scientific research since the program launched in 2022. This would not have been possible without the incredibly generous support of our community, whose donations fund our research grant opportunities. Through this support, two new research grant opportunities were launched this year: the Clinical Scholar Award and the Integrative Medicine Award.

# THE CLL SOCIETY RESEARCH PROGRAM

CLL Society is one of the only nonprofit organizations in the United States that is dedicated exclusively to funding research for CLL and SLL. 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's Research Program prioritizes research in the following 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**

# YOUNG INVESTIGATOR AWARD

This award supports the academic career development of scientists who are early in their careers. It encourages the next generation of scientific leaders to perform research that is specific to CLL / SLL.

## Prajish Iyer, PhD

**City of Hope, Duarte, CA**

Dr. Iyer's research aims to understand the cellular changes that drive the progression of CLL into Richter's Transformation.

# CLINICAL SCHOLAR AWARD

The Clinical Scholar Award supports scientific research that advances the treatment or prevention of CLL and is available to physician-scientists with an established career in CLL research.

## Jennifer Brown, MD, PhD

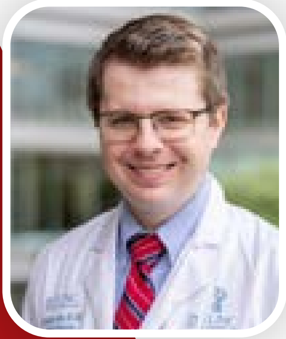
**Dana-Farber Cancer Institute, Boston, MA**

Dr. Brown's study aims to test whether combining venetoclax, obinutuzumab, and a new drug called roginolisib (a PI3K delta inhibitor) can improve remission duration and depth for patients with CLL who relapse after treatment with a BTK inhibitor.

# INTEGRATIVE MEDICINE AWARD

This award supports early research on using integrative approaches to address health challenges in CLL and combining these practices with traditional cancer treatments to improve patients' overall well-being. Read more about how these awards were made possible in the Empowering Philanthropy section.

> *Spiritual Advocate program for those of us who wish to avail themselves of it. I had the pleasure of working with Rabbi Rebecca Kamil. She is OUTSTANDING and wonderful to talk with regarding my current challenges. I REALLY appreciate CLL Society for this service. I will continue to support CLL Society to the best of my ability. Thank you!.*
>
> ***- Donald G. James***
> ***CLL patient since 2024, California***



## Christopher Jensen, MD, MSCR

**University of North Carolina-Chapel Hill, Chapel Hill, NC**

Dr. Jensen's study aims to understand cancer-related fatigue in CLL by gathering patient feedback, evaluating its effect on quality of life, and exploring whether integrative medicine approaches can help reduce fatigue.

*This 2024 Integrative Medicine Award was made possible through generous donations made by those in our community as part of a matching grant from the Sim Einstein Research Foundation, Inc. and Vigyan Singhal.*

## John Byrd, MD

**University of Cincinnati Cancer Center, Cincinnati, OH**

Dr. Byrd's study examines how probiotics might change the gut microbiome to reduce inflammation and improve overall health in CLL patients.

*This 2024 Integrative Medicine Award was made possible through the generosity of Vigyan Singhal.*


VOLUNTEER

# EMPOWERING COMMUNITY ENGAGEMENT AND ADVOCACY

As part of our ongoing commitment to reaching patients where they receive care, CLL Society continues to expand the reach and impact of our Equitable Community Care Outreach (ECCO) initiative. ECCO focuses on connecting with the community healthcare setting, where the majority of individuals living with CLL are diagnosed and treated.  Through this initiative, we are building meaningful connections and addressing health disparities by bringing education and support resources to underserved populations.

In 2024, ECCO helped us deepen our community presence. We are proud to share key accomplishments that reflect our progress in building more equitable access to care.

In parallel, CLL Society remains committed to recognizing and addressing the diverse needs of all individuals living with CLL. We report on health equity in CLL to raise awareness of how the disease affects different demographic groups in distinct ways. We also actively advocate with government agencies and policymakers to advance policies that will improve the lives of those living with CLL/SLL.

# CLL SOCIETY TABLE TALKS

In 2024, CLL Society launched ***Table Talks,*** a new educational initiative that marked the return of live, in-person events. These events are designed to bring together all key players involved in the care of individuals with CLL within the community-based setting.

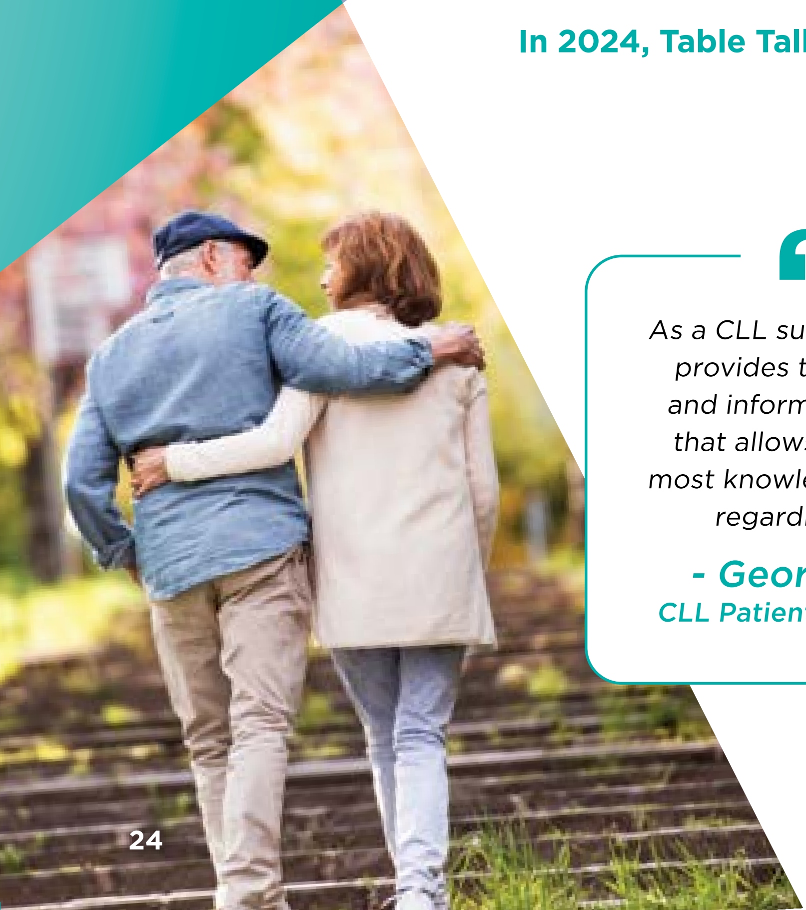
Each event gathers healthcare professionals, patients, care partners, and patient advocacy groups for an engaging roundtable discussion with CLL experts practicing in the academic setting. Together, they delve into CLL and SLL treatment options and available support resources.

**In 2024, Table Talk events were held in:**

**Minnesota**

**Idaho**

**North & South Carolina**



> *As a CLL survivor, CLL Society provides the most relevant and informative information that allows me to make the most knowledgeable decisions regarding my health.*
>
> **- George DeLong**
>
> *CLL Patient since 2011, Texas*

The primary goal of *Table Talks* is to spark robust conversations around disease education, innovative treatment options, best care practices, and patient self-awareness. Through this initiative, CLL Society is positioning itself as a trusted partner for community providers while championing a patient-first approach centered on education, access to care, support, and empowerment. We are excited to continue hosting Table Talk events in more cities nationwide.

# CONNECTING WITH COMMUNITY HEALTHCARE PROVIDERS

In 2024, CLL Society exhibited at more than **15 live and virtual hematology and oncology conferences** across the country. These events provided the opportunity to connect directly with healthcare providers across various practice settings, many of whom are caring for individuals with CLL/SLL in the community-based setting.

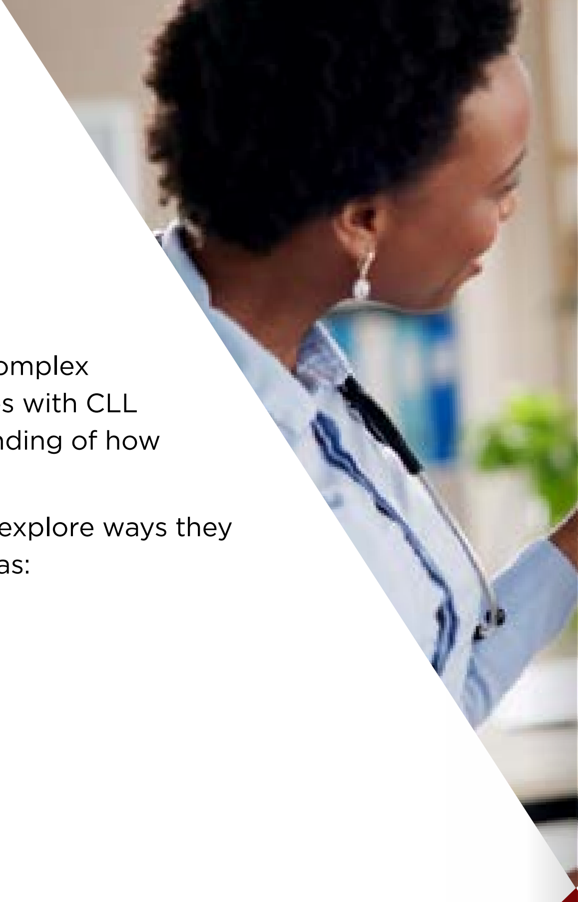
Through these conferences, we are increasing awareness among community healthcare providers about CLL Society's mission and the comprehensive education and support resources we offer to help their patients.

The response has been outstanding, with over **1,500 conference attendees** requesting follow-up from CLL Society to learn more about the resources available to their patients. As a direct result of this outreach, CLL Society distributed **57,820 pieces of printed patient education materials** to healthcare providers across the country and sent full resource boxes to **30 community practices** upon request. These materials included:

- **CLL disease-specific informational handouts**
- **CLL medication fact sheet**
- **Overview of CLL Society services brochure**
- **CLL Society Support Groups Brochure**
- **Resources for Veterans with CLL handout**
- **CLL Society connect postcard**

By building strong connections with healthcare providers in the community, we are able to reach patients directly where they receive care, ensuring they have access to trusted information and support tailored to their needs.

# TRANSLATING HEALTH EQUITY RESEARCH IN CLL



As part of our commitment to supporting every individual living with CLL/SLL, CLL Society breaks down complex scientific research on health disparities into clear, patient-friendly summaries. We recognize that experiences with CLL can differ based on race, ethnicity, age, income, and other factors, and we aim to foster a greater understanding of how these differences influence care experiences and treatment outcomes.

By sharing this research in an easy-to-understand format, we highlight the real-world impact of disparities, explore ways they can be addressed, and acknowledge progress being made over time.  In 2024, we covered key issues such as:

- **Diversity and representation in clinical trials and how to improve it**
- **Disparities in patient outcomes and survival rates across race, ethnicity, and socioeconomic status**
- **Differences in disease biology and treatment experience among racial and ethnic groups**
- **Access to and use of palliative care in the CLL community**
- **Unique characteristics and outcomes of CLL in adolescents and young adults**

# ADVOCATING FOR YOU

The CLL Society Policy Institute was busy throughout 2024, advocating and providing a unified voice to support the needs of all people living with CLL/SLL. As in the past, our priority areas of focus continue to be:

- **Ensuring access**
- **Protecting innovation**
- **Elevating the needs of the immunocompromised**

Guided by these pillars, the CLL Society team worked directly with federal agencies, including the FDA and Centers for Medicare and Medicaid Services (CMS), providing written briefings, offering expert and patient testimony, and coordinating with partners to ensure we spoke with the loudest possible voice. CLL Society took the lead in working with the CMS as they worked to implement parts of the Inflation Reduction Act that directly affected pharmaceutical cost, access, and investment.

# 2024 KEY ADVOCACY ISSUES

Ensuring that the impact on patients remains a central consideration throughout the implementation of the Inflation Reduction Act (IRA) while providing ongoing guidance to CMS to strengthen its engagement with patients and patient organizations during the rollout.

Pushing for CMS to include patient perspectives in decisions around the Drug Price Negotiation Program and Medicare Prescription Payment Plan.

Directly amplifying the patient voice during the IRA implementation, with several team members engaging in conversations with CMS across multiple platforms.

Joining with other patient advocate organizations to tell policymakers of our growing concern that health plans have been ‘carving out’ specialty drugs from patients’ benefit and urging CMS to review health plan formularies to enforce the requirements that Part D plans include all or substantially all cancer treatments within the “protected classes” on the plan formularies.

Encouraging better education and patient-friendly information around cost smoothing for patients relying on Medicare or Medicaid.

Calling for COVID-19 vaccine availability early in the season in a letter co-signed by several patient advocacy organizations

**Click to learn about our 2024 advocacy, including our webinar on the Inflation Reduction Act (IRA) and Medicare changes:**

*https://cllsociety.org/2024/08/your-medicare-guide-tackling-costs-and-answering-your-questions/*

# EMPOWERING PHILANTHROPHY

CLL Society invites all who are passionate about improving the lives of those impacted by CLL/SLL to join us in our mission. The progress we make each year is only possible because of the generosity and dedication of our incredible supporters. In 2024, several notable fundraising efforts played a vital role in advancing the work of CLL Society and expanding our reach to those impacted by chronic lymphocytic leukemia (CLL).

# INTEGRATIVE MEDICINE AWARD MADE POSSIBLE THROUGH COMMUNITY SUPPORT

Thanks to the extraordinary generosity of Vigyan Singhal and the Sim Einstein Research Foundation, Inc. (SERFI), we established a new research funding opportunity in the field of integrative medicine for CLL/SLL. Together they provided half the funds necessary to create CLL Society's 2024 Integrative Medicine in CLL Award.

Integrative medicine is a patient-centered, evidence-informed field of comprehensive cancer care that combines conventional cancer treatments with practices like mind-body techniques, natural products, and lifestyle modifications.

It is the only form of therapy that truly holistically addresses a patient's well-being. Mr. Singhal and SERFI were inspired to support more scientific research in this area to promote optimal health and well-being for those living with CLL.

Over the course of a 10-month campaign, members of the CLL/SLL community rose to the challenge and completed the match, ultimately raising the full **$122,000** required to fund the award.

From this incredible show of community support, Mr. Singhal decided to take his generosity even further to fund a second 2024 Integrative Medicine in CLL Award, elevating the impact of this initiative.

We are immensely grateful to Vigyan Singhal and the Sim Einstein Research Foundation, Inc., as well as every donor who contributed to this campaign. We could not provide this vital research funding without you. Your commitment is advancing research that cares for the whole patient.

# CELEBRATING LONG LIVES 5K WALK AND RUN

The third annual Celebrating Long Lives event took place on May 11, 2024, uniting 267 patients, care partners, loved ones, and supporters from across the country. We were especially moved to see many of our support groups gathering in person to participate together, forging deeper connections and strengthening their networks of support.

This meaningful annual event not only recognizes those living with CLL/SLL but empowers our community to come together in solidarity to support one another and take an active role in raising funds for the mission of CLL Society. At the 2024 event, our community raised $58,710 to directly support those impacted by CLL/SLL.

## 2024 Participants

**Top Fundraisers:**

- Neil Muchin: $4,060
- Brian and Patty Koffman: $3,394
- Anna Turski: $3,110

**Top Teams:**

- 3 Body Solution: $4,924
- Hope Society: $2,845
- Rochester CLL/SLL Group: $2,626

> “ ”
>
> *I feel so blessed that two years after my CLL/SLL diagnosis and immediately beginning treatment for SLL, I was still feeling strong and healthy enough to walk the Celebrating Long Lives 5K this past Saturday, with my family there to support me. It was a fun and easy way to raise funds for the CLL Society, and now we plan on participating every year.*
>
> ***- Sue Conrad-Kanstul***
>
> ***(second from the left), SLL Patient since 2022, California***

## Board of Directors Doubles the Impact for Blood Cancer Awareness Month

September is Blood Cancer Awareness Month (BCAM), a dedicated time to raise awareness and show support for those living with blood cancers like chronic lymphocytic leukemia or small lymphocytic lymphoma (CLL/SLL).

In 2024, members of CLL Society's Board of Directors came together to provide a **$17,500 matching gift** opportunity in honor of this important month.

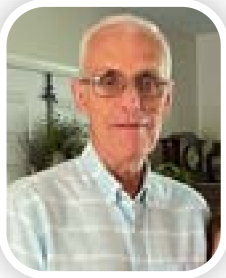
The response from our community was nothing short of monumental, **raising a total of $61,973,** including the match, to support and improve the lives of those living with CLL/SLL.

GIVING TUESDAY

## Giving Tuesday

On Giving Tuesday, our community demonstrated their remarkable dedication to our mission, raising an impressive **$113,270** to provide life-saving support, education, advocacy, and research for the CLL/SLL community.

We are especially grateful to an anonymous donor who generously contributed a **$25,000 match**, inspiring even more individuals to join the campaign. This global day of generosity continues to be the single largest day of giving for our community, highlighting the power of collective action.



> *We are inspired to give on Giving Tuesday in gratitude for all the invaluable information and guidance offered by the CLL Society!*
>
> ***- Austin Willi***
>
> *CLL Patient since 2017, Pennsylvania*

## In Honor and Memory

Tribute giving is a heartfelt way to honor those who have played a pivotal role in your CLL journey, whether it is a partner, family member, friend, nurse, doctor, or spiritual leader who provided crucial support. It is also a powerful way to remember a loved one lost to CLL/SLL. By making a gift in their name to CLL Society, you not only express your gratitude for their impact on your life but also help us support and improve the lives of all those navigating life with CLL/SLL.

In 2024, many individuals came together to donate over $7,000 in memory of Jennifer Creager, who lived courageously with CLL for eight years before passing away just before the end of 2023. Jennifer was a valued member of the Orange County Support Group, the very first support group established by CLL Society, and will be deeply missed by all those who knew her. Gifts made in her memory contribute to CLL Society's mission, ensuring continued support for others impacted by CLL/SLL.

## Exploring the Power of Legacy Giving

Legacy giving may seem complicated or intimidating, but it doesn't have to be! It is a profound and lasting way to make a meaningful difference for the CLL/SLL community, and anyone can do it. By choosing to leave a legacy gift to CLL Society, you are making a significant commitment to shaping a brighter future for those living with CLL/SLL.

Our webinar, **A Brighter Future for CLL: Learn How Your Legacy Can Have a Lasting Impact**, explores what legacy giving is and how you create lasting change through this type of gift. In 2024, CLL Society took additional steps to simplify and clarify the legacy giving process by updating the information on our website, making it more accessible for everyone.

If you are interested in making a legacy gift, we invite you to visit our Legacy Giving webpage, watch the webinar, or reach out to CLL Society directly. We welcome the opportunity to have a conversation and help you find the best way to make an impact that aligns with your wishes.

# YOUR SUPPORT EMPOWERS OUR WORK

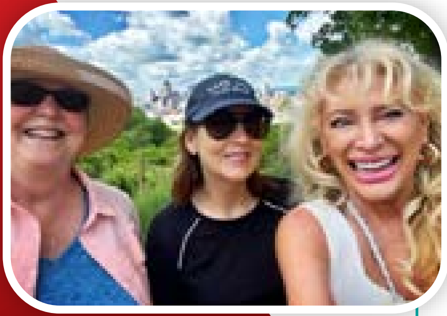
**A note to our wonderful donors,**

Supporting and empowering the CLL/SLL community is at the heart of our mission. As we continue to expand CLL Society's services and impact, we are steadfast in our commitment to empowering those living with CLL at every stage of their journey.

This is possible because you support our mission. Your contributions provide the support that empowers us to grow each year and help more people in more ways. CLL Society is a small but rapidly growing organization, with no government funding, and all of our educational resources and support programs are provided at no cost. It is you – our donors – who empower us to do better every year.

Thanks to the generosity of our CLL Community, 2024 was another record-breaking year for our fundraising program. This success is important because so much of what CLL Society does relies on 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 people are living with this disease, we will be here providing empowering 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. 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.



> *When I was diagnosed with CLL in 2017, I knew nothing about the disease and knew no one with it. It was scary. CLL Society changed that. CLL Society has educated and supported me.*
>
> ***- Laura Alexoff***
>
> ***CLL Patient since 2016, CLL support group facilitator since 2020, Ohio***

There are a variety of ways in which you can provide meaningful support for the work of CLL Society. You can always mail a check or make a gift 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 your family first.
- **If you own appreciated stock**, consider donating shares directly to CLL Society to reduce your tax burden.
- **CLL Society now accepts gifts of real estate.** You can learn more at: ***www.cllsociety.givingproperty.org/home***
- **If you have an IRA, you may be able to donate all or part of your annual required minimum distributions (RMDs).** 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, directly from your IRA, and pay no income tax on this amount.
- **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.
- **Become a CLL Society Sustainer** by starting a monthly recurring donation. Your ongoing support ensures we are able to continue our work year-round.
- **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@cllsociety.org, or call (860) 575-2605. Together, we can figure out which giving option is best for you.

**Thank you for making a difference!**

**Ron Katz**
*Development Director*

# 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.

## 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 2024 IAC Members.

### Platinum Members

AstraZeneca

BeOne

### Gold Members

abbvie

Genentech
A Member of the Roche Group

### Silver Members

Adaptive
biotechnologies

Lilly

pharmacyclics
An AbbVie Company

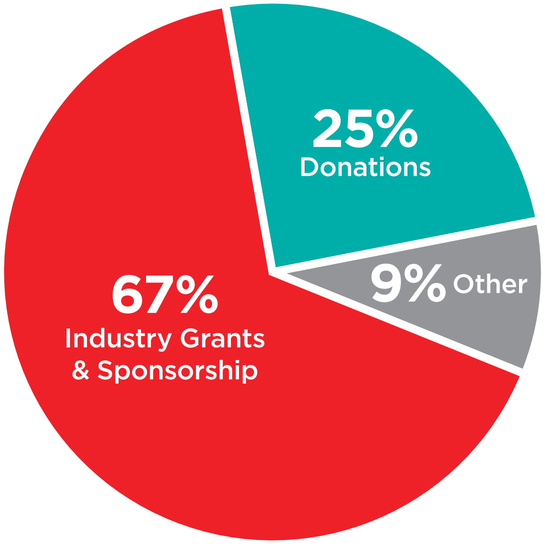
## Additional Supporters

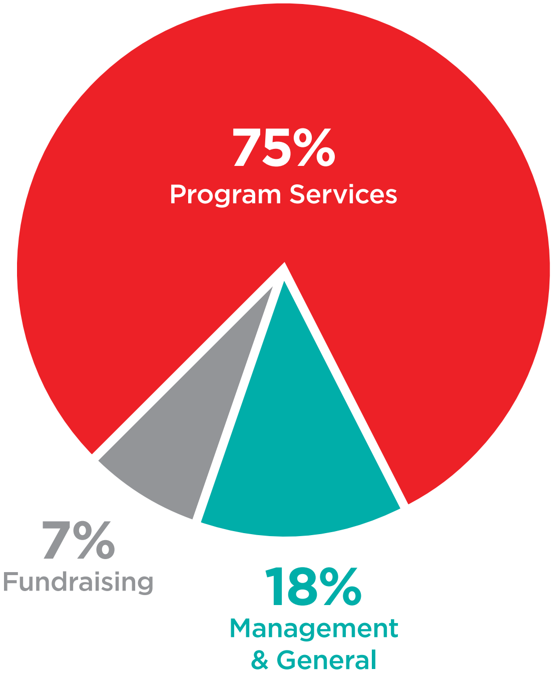
- **AbbVie**
- **Adaptive**
- **AstraZeneca**
- **BeOne**
- **BMS**
- **Carna Biosciences**
- **Galapagos**
- **Genentech**
- **Insperity**
- **Lilly**
- **Merck**
- **Octapharma**
- **PAN Foundation**
- **PCYC/Janssen**
- **UT Health San Antonio**

# 2024 FINANCIALS*

## Revenue

| | | |
|---|---|---|
| **Industry Grants & Sponsorship** | **$2,507,460** | **67%** |
| **Donations** | **$918,825** | **25%** |
| **Other** | **$322,551** | **9%** |
| **TOTAL** | **$3,748,836** | |





## Expenses

| | | |
|---|---|---|
| **Program Services** | **$2,531,116** | **75%** |
| **Management & General** | **$610,011** | **18%** |
| **Fundraising** | **$233,372** | **7%** |
| **TOTAL** | **$3,374,499** | |

**Pre-audited projections*

# 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 2024. 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.

## $20,000+

1 Anonymous Donor
James Florczak and Nancy Friedland
Douglas A. Himes
Singhal-Bhushan Charitable Fund
Daniel Springer

## $10,000–$19,999

3 Anonymous Donors
Insull Giving Fund
Warren Irwin
Thomas Klein
Dr. Brian and Patricia Koffman
Sim Einstein Research Foundation, Inc. (SERFI)
Cheryl & David Stern Charitable Fund
William J. Wishner Charitable Fund

## $5,000–$9,999

4 Anonymous Donors
Urs and Karen Bauder
Erin Bawol
Iorio Family Fund
The Kaczmarek Family Charitable Fund
Robert Levis
Karen Marino
Howard and Barbara Massey
Judy Metzger
Rebecca Newton
Don and Donna Payerle Donor Advised Fund
The Edward and Joyce Ratner Philanthropic Fund
Ken Shifrin
Kevin and Lindsey Simmonds Fund
Dennis Vicars and Lisa Driver Family Fund
Douglas and Kerry Vincent
Robert and Wanda Zimmer Helping Hands Fund of the Orange County Community Foundation

## $1,000–$4,999

8 Anonymous Donors
The Amster Family Charitable Fund
John Backus
Stacy Barber
Janis Benach
Lois Benedetti
Jane Bernstein
Matthew Berry
John and Kathleen Bethell
Linda B. Blackburn
Victoria Bour
Mark and Ruth Brenner
Eliza A. Bridgman
Anthony Bui
Robert Burke
Pamela Burkett Donor Advised Fund
Anne Byerly
Nancy Capra
Sarah Castro
Karen Cauayani
Stephen S. Chapman
Chaim and Tikvah Chudler Donor Advised Philanthropic Fund
Conner Giving Fund
Margaret and Frederick Conroy
Garrett and Denise Covington
Dawn Davenport
Scott and Mary Davis Giving Fund
Mae H. Dea Donor Advised Fund
George Deichert
James and Susan Durst
Val and Don Edwards
Ramses Erdtmann
Steve Eriksen
Michael and Rose Fabian
Lisa and Jerome Feldman
Flachs Family Fund
Michael Freed
Richard and Mary Gaissert
Joseph and Maureen Geller Giving Account
Frank Gerig
Brien Gibson
M. Glickfeld Family Fund
Graham and Mengler Giving Fund
Michael Green, MD
Russell Haag
Florence D. Hafter Family Foundation
Robert Hander
Jim Hardy
Orrin Heller
Leonard Rossoff and Eileen Hilton Donor Advised Fund of the Hawai‘i Community Foundation
Frank Hochfeld
Jerry Hodges
Harold B. and Alice Hoffman Donor Advised Fund of the Jewish Community Foundation of the Milwaukee Jewish Federation
Bob Holtzapple
James Horne
Janice Jackson
Jaffe & Wall Giving Fund
Jason Family Foundation
Daniel E. Johnson and Lisa A. Freundlich Charitable Fund
Amy Johnson
Plaskett Kordisch Charitable Gift Fund
Barbara Kositchek
William Kyburz
Laurence and Linda Lannom
Letts Family Trust
Bruce and Kathleen Levi
Art Levit
Joseph L. Liegl
Robert Mansfield
Larry Marion and Leslie Eisenberg
Salvatore Marranca
Katherine Matthews
The Mary A. Mettler Fund
The Carl and Beth Migliazzo Charitable Fund
Mark Moler
Anthony Monaco
Carol Muchin
Christopher Nolan
Stuart Ott
Balbir Singh Patpatia
Perfect Plank
Emily Plishner
Thomas Podesta
Doug Post
James O. Rauch
Daniel Reed
Joe and Marlise Ricci Charitable Gift Fund

# DONOR ACKNOWLEDGMENTS

## $1,000–$4,999 (Continued)

Michael Ricinak
Michael Rossoni
Janet Rost
True Ryndes and James Anderson
Salamone Family Charitable Fund
The Roger and Nancy Sayler Charitable Fund
David Schneider
Jeff Schumer
Hina Sharma
Shebowich/Stempien Fund
Sue Shindell
Maxine Sindledecker
Richard Small
The Douglas A. & Phyllis G. Smith Charitable Trust of The Columbus Foundation
Ivan Starcic
Harvey H. Stern
William and Cheryl Struble
The Sutton Family Charitable Fund
Brad Teague and Nancy Byers-Teague
Arnold Visnick
Vitulli Family Foundation of Park City Community Foundation
Karen Ann Wald
William Walker
Patricia Ann Wallace
Holly Watson-Evans
Sarah Williams
Thomas Wisnowski Fund
Harvey Yavil
Cami Young
Doug and Lynette Zezoff Donor Advised Fund

## $500–$999

17 Anonymous Donors
Mike Allemang and Janis Bobrin
Deborah Ayers
Joel Bacon
Robert and Ramona Barton
Michael Berman
Judy Bjorke
Steven Bloom
Edward and Joyce Brand
Judith Brody
The Brown Family Fund
Ron Campbell
Deirdre Campbell
Louise Capraro
Charlene Carter
Joshua Castleman
The Konicki-Chenard Fund
Nick Christie
The Chrisman Family Fund
Russell Clayshulte
Franklin and Frances Conn
Susan Conrad-Kanstul
Brian Cothroll
Matthew Davids, MD
Stephen Davis
Annette DeBois
George DeLong
William Denton
Leslie Jane Easterly
Steven Eisenberg
Liz Eldakar
Peter V. Elting
Terry and Donna Evans
Michael Fein
Jill Feldman
Roberta and Jose Franco
Judith and Roger Frank
Tiffany Frazier
Richard Friedman
Beverly and Bill Goldner Charitable Fund
Martin Goldrosen and Susan Arbuck
Gregory Groce and Rachel Chrobak

## $500–$999 (Continued)

Gutfreund Family Fund
Leon Hankin
Scott & Debby Hatch Gifts
Janet Heide
Steven Helf
Sharon M. Heller
M. Elise Huggins
Edward and Dorothy Jaasma
James Family Donor Advised Fund
Jay Johnson
Richard Johnson
Daniel Kaplan
Paul and Marie Kenyan
Jonathan Khuner
Walter King
Sue Kmetz
John Korach
Gary Lansman
Miriam Lawrence
Nancy Leutner
John Lewin
Robert Linderman and Ida Granowitz
Leslie and Kevin Lloyd
LSLK Fund
Kathryn Lyons
Thomas and Jenny Marx Giving Fund
M.A.S. Family Fund
Douglas Maxwell
McConneloug Donor Advised Fund
David Burr Melamed
Olga Milosavljevic
William Minner
Diane Mitchell
William Mitchell
Elaine Morris
Julie Murphy
Debra Mykkanen
Peter Newton
Kristine Nielsen
Eileen Nolan
James Oakley Donor Fund
Mark Owens
Paul Pazandak
Johnny Phillips
Margaret Phillips
James Plotkin
Douglas Poad
Rick and Debbie Powell
James Proman
Patrick Quick
Christine Ramezzano
Mary and Richard Raub
The Anita and Paul Rickershauser Fund
David I. Roberts
Gayle S. Rose
Tom & Lucinda Sands
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VHC Health - COPS Nursing Staff
David Wade III
Nancy Wagman and David Danning
Charles Waldron
John L. Malay Jr. and Melinda Watson
Lynn Weston
Deborah Lewis Williams and Michael Eugene Williams
Stuart Willner
Fanling Yang
Lucia Zimmitti
Neil Zolkind

*We made every effort to accurately recognize the donations listed above. If a donation is missing or misrepresented, we are truly apologetic. Please contact CLL Society for a resolution. An up-to-date 2024 donor recognition page can be found on our website.*

# CLL SOCIETY

## Smart Patients Get Smart Care™

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support@cllsociety.org

Facebook: @CLLSociety
LinkedIn: @cll-society
X: @CllSociety

Learn how you can support the work of CLL Society by visiting:

**www.cllsociety.org**

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