



# 2022

ANNUAL REPORT

## ESTABLISHING NEW PATHWAYS



CLL SOCIETY

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## 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.

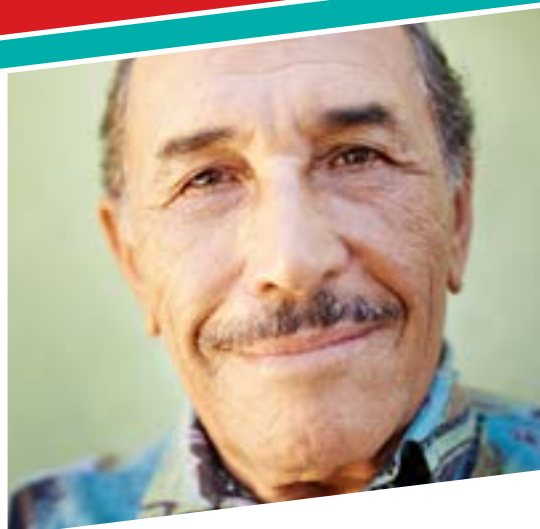


## ESTABLISHING NEW PATHWAYS

CLL Society's vision is to see a world in which the entire chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) community can equitably access quality education, support, and care, to lead healthier and richer lives. For this vision to become a reality, we are dedicated to playing an active role in forming it, piece-by-piece, and in partnership with patients, caregivers, loved ones, advocates, healthcare professionals, fellow patient advocacy organizations, and industry partners.

By focusing on our core pillars of education, support, advocacy, and research, our reach and impact is expanding. Our pursuit of enhancing the future for patients and caregivers makes us committed to continuously **establishing new pathways**. In 2022, we forged essential new pathways in our core pillars, including launching the CLL Society Research Program, unveiling a new website, and expanding advocacy and policy efforts.

Join us as we embark on new paths to improve health outcomes and establish equitable access to vital care and support for those impacted by a diagnosis of chronic lymphocytic leukemia/small lymphocytic lymphoma.



# PATIENT STORY: MEET STUART



My name is Stuart Willner. I was diagnosed with chronic lymphocytic leukemia (CLL) in November of 2019 during a routine physical exam at the age of 67. It was a frightening and daunting moment given my total ignorance of this cancer. Living in Seattle, Washington I am fortunate to have as a provider the Seattle Cancer Care Association, a Fred Hutchinson Cancer Research Center affiliate, where I received an immediate and comprehensive diagnosis from a veteran hematological oncologist. I was diagnosed with Trisomy +12, which is assessed as an intermediate-risk mutation, and given a 3-to-5-year time frame for entering treatment.

During the three-plus years since my diagnosis, I have been in watch and wait (worry). I have relied on CLL Society as my primary source of information and access to the knowledge I need to speak confidently with my provider. “CLL Society: This Week,” a weekly email, links me to an unending supply of medical professionals from the academic and working world through easy-to-understand video interviews and other resources about everything to do with CLL biology, therapies, clinical trials, and living with CLL, including support for both the patient and the caregiver’s mental and financial well-being.

At the moment of writing this, I have had no treatment. But my recent blood work has shown a doubling of my white blood cell count which is predicate to having treatment in the nearer future. While this has been a sad notification, it has not been unexpected. Notwithstanding, among CLL Society’s many services I have been able to join a CLL Society Support Group, an on-line monthly Zoom meeting which is composed of many individuals with CLL who are at various stages of their experience with CLL. As I have been comforted by my learning and have in this way taken control of my future, my CLL fellow travelers are a great comfort to me. The monthly meetings are a place where we can speak openly about our lives and find the nurturing support that we need from each other. CLL Society is a treasure for all who would choose to avail themselves of its generosity.

## **Stuart Willner**

CLL Patient since 2019

Washington



# YEAR IN REVIEW



**\$619,918**

donated by individuals



**789**

new CLL Society Support  
Group members



**11**

live educational programs  
reaching a combined total of

**4,596**

attendees



**55**

expert CLL healthcare  
provider interviews



**120**

individuals connected  
to expert care through the  
Expert Access™ Program



**1,652**

questions answered by expert  
healthcare professionals through the  
Ask the Experts program



awarded the first CLL Society Research Program Young Investigator Award

# EXECUTIVE STATEMENT

## Dear Friends,

We have another fantastic year of accomplishments at CLL Society to celebrate. For those that have been following us for a long time, thank you for your support and for putting your trust in us. For those that are new to our community, welcome!

We are so proud of the continued success of our programs, and have been humbled to watch our audience and our capacity grow year after year. Our strength is attributable to our outstanding community who keeps coming together with the shared vision of *a world in which the entire CLL/SLL community can equitably access quality education, support, and care, to lead healthier and richer lives.* Our Patient Advisory Board, Medical Advisory Board, Board of Directors, staff, generous donors and volunteers, and the many individuals affected by CLL/SLL who attend our events, give us feedback, respond to surveys, and engage with our content are all playing an important role in making CLL Society a leading catalyst for change in CLL care. We know it is these same people who will help us achieve our visions for the future.

CLL Society was founded on the concept of 4 pillars: Education, Support, Advocacy, and Research. We have a long history of work related to the Education and Support pillars, having delivered hundreds of educational activities over the years, and growing our Support Group population to over 3500 members across the country. In our early years, CLL Society's Advocacy focus was primarily teaching patients how to advocate for their own best care, while our Research was primarily focused on studies aimed at understanding the CLL patient experience. In 2022, we stretched ourselves to forge new pathways in the Advocacy and Research pillars, with the intention of making a stronger, systemic impact that will affect the future of the treatment landscape in CLL. Our definition of Advocacy has expanded to include taking on policy issues at the highest levels, and fighting on behalf of patients on issues of importance that impact their quality of life. Likewise, we broadened our definition of Research to include awarding grants to young physicians interested in solving unmet clinical needs in CLL.

In 2022, we took our first steps onto these newly established pathways that will lead us to the future we envision for the entire CLL/SLL community, but there is a long and exciting journey ahead. We look forward to walking down these paths with you.

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



**Brian Koffman, MDCM**  
Co-Founder



**Carly Boos, MEd, MBA**  
Executive Director



**Steve Bloom**  
President & Chair

# BOARD OF DIRECTORS

**Steve Bloom**

*President & Chair*

**Sandy Bihlmeyer, MEd**

*Secretary*

**Robert Levis**

*Interim Treasurer*

**Brian Koffman, MDCM (retired), MEd**

*Member at Large*

**Susan O'Brien, MD**

**Keith Watson, PhD**

# CLL SOCIETY STAFF

**Brian Koffman, MDCM (retired), MEd**

*Chief Medical Officer, Executive Vice President, Co-Founder*

**Carly Boos, MEd, MBA**

*Executive Director*

**Patricia Koffman\***

*Communications Director, Co-Founder*

**Liza Avruch, MPA**

*Program Director*

**Robyn Brumble, MSN, RN**

*Director of Scientific Affairs and Research*

**Brad Hedrick, MSCIS**

*Information Technology Director*

**Nicole Kamphuis, MPA**

*Development and Communications Manager*

**Fernando Parra Chong**

*Strategic Partnerships Specialist*

**Nancy Day**

*Program Coordinator*

**Albie Suozzi**

*Executive Assistant*

**Saira Sultan, JD**

*Healthcare Advocacy and Policy Consultant*

\*Retired in 2022

# MEDICAL ADVISORY BOARD

**Anthony Mato, MD, 2022 Chair**

*Director of CLL Program*

Memorial Sloan Kettering Cancer Center, New York

**Alexey Danilov, MD, PhD, 2022 Co-Chair**

*Professor and Co-Director, Toni Stephenson Lymphoma Center*

City of Hope, California

**Matthew Davids, MD**

*Associate Director-Center for CLL/Professor of Medicine*

Dana-Farber Cancer Institute, Massachusetts

**Brian Hill, MD, PhD**

*Director, Lymphoid Malignancies Program*

Cleveland Clinic Taussig Cancer Center, Ohio

**Nicole Lamanna, MD**

*Associate Clinical Professor of Medicine in the Hematology/Oncology Division*

Columbia University Medical College, New York

**Javier Pinilla-Ibarz, MD, PhD**

*Senior Member and Head of Lymphoma Section in the Department of Malignant Hematology*

H. Lee Moffitt Cancer Center and Research Institute, Florida

**Sameer Parikh, MD**

*Assistant Professor of Medicine and Oncology*

Mayo Clinic, Minnesota

**Alan Skarbnik, MD**

*Director of the Lymphoma & CLL Program*

Novant Health, North Carolina

**Deborah Stephens, DO**

*Assistant Professor of Hematology and Hematologic Malignancies*

Huntsman Cancer Institute, Utah

# PATIENT ADVISORY BOARD

**Bruce Wright, Chair**

*Patient*

**Elizabeth Dechen**

*Patient*

**Terry Evans**

*Patient*

**Stephen Feldman**

*Patient*

**Barbara Massey**

*Patient*

**Howard Massey**

*Caregiver*

**Raye Murphy**

*Patient*

**Haleh Simi**

*Patient*

**Dan Patterson**

*Patient*

**Jolianne Jones**

*Patient*

**Christina Rodriguez Fuller**

*Patient*

**Wilbur (Rich) Richburg**

*Patient*

**Michael Turner**

*Patient*

**Doreen Zetterlund**

*Patient*

**Albie Suozzi**

*Patient*

## International Patient Advocates

**Michael Rynne**

*Caregiver*

Ireland

**Deborah Sims**

*Patient*

Australia

**Nick York**

*Patient*

United Kingdom



# PATRICIA KOFFMAN RETIREMENT



After nine years of dedicated service to CLL Society, Patty Koffman, co-founder and communications director for CLL Society, officially retired from her full-time position with CLL Society on April 30, 2022. Rest assured that Patty remains deeply invested in and committed to CLL Society's mission and will continue to serve CLL Society in a volunteer advisory capacity as needed.

Patty Koffman's engagement with CLL began in 2005 when her husband, Dr. Brian Koffman was diagnosed. Patty's first goal was to save one person's life- Brian's- but as she and Brian learned more about the disease and the needs of CLL patients, they became determined to help others with CLL through peer support and delivery of credible, timely information about the disease as well as the changing treatment landscape. In 2013, just as promising treatments were becoming available to patients, Patty and Brian launched the nonprofit CLL Society that today provides critical information, resources, and programs to tens of thousands of people living with CLL.

In the early months and years, Patty did the hard work of establishing the infrastructure required to operate a nonprofit, while leading the production of our conference coverage expert interview series, bringing the latest advancements in CLL science forward to patients, and managing all the daily activities required to make CLL Society successful. As our staff team grew, Patty was able to better focus her attention on developing our voice and brand in a way that would sustain the organization for years to come. Patty's contributions to CLL Society over the past nine years are far too many to name, but include authorship of our weekly newsletter, conceptualization of our Test Before Treat program, management of our social media channels, and regular speaking engagements for CLL Society and other cancer organizations' activities. Her capstone project was serving as a critical team leader on the redesign of CLL Society's website, where she championed the critical importance of the patient voice and patient experience in all phases of the design process.

Patty Koffman has always led with creativity, compassion, and generosity. Her gifts to the CLL community are immeasurable, and her legacy with CLL Society will live on through the staff, boards, and volunteers who have benefited from her counsel and mentorship.

While we will miss working with Patty on a daily basis, we are grateful to know she will continue to be a resource to the organization as it grows and evolves. Patty has certainly earned her retirement, and we hope you will join us in wishing her the very best as she embarks on this next chapter of her life.



# CLL/SLL EDUCATION & SUPPORT

Providing CLL/SLL patients, caregivers, and loved ones with high-quality, physician-curated education and support services is the backbone of our organization. This year, we established several new initiatives to connect our community with the best possible care.



# CLL SOCIETY DEBUTS NEW WEBSITE



The launch of CLL Society's new website in late April 2022 marked the culmination of a more than yearlong effort to deliver education and support to the chronic lymphocytic leukemia/small lymphocytic lymphoma community in the most accessible way achievable. When designing the website, the primary focus was to create a user-friendly experience that facilitated seamless navigation and quick access to essential information.

A thoughtful reorganization of content aimed to provide better access to resources for those newly diagnosed, education on various treatment options and clinical trials, COVID-19 news, CLL Society support programs, stories and testimonials from fellow CLL/SLL community members, and more to those impacted by a diagnosis of CLL/SLL.



## Mental and Physical Health Resources Webpage



With the new website, CLL Society introduced a dedicated section on mental and physical well-being for patients and caregivers. A diagnosis of cancer goes beyond treatment decisions and has a profound impact on every aspect of an individual's life. The Mental and Physical Health webpage offers support through articles, recorded webinars, and interviews covering a wide range of topics.



# CLL SOCIETY PATIENT AND CAREGIVER SUPPORT GROUPS

Ongoing concerns related to immune suppression have prevented a return to in-person support group meetings, yet virtual support group meetings have remained a crucial and reliable source of peer-to-peer support for patients and caregivers.

## MEMBERSHIP

 **31%**  
by the end of 2022



**326**  
individuals brought  
together through  
**WATCH AND WAIT**  
support groups.



## Watch and Wait CLL Society Support Groups

The experiences, emotions, and priorities for an individual in the “watch and wait” period of CLL are unique from when one enters active treatment. While participating in a support group with individuals who have begun treatment holds great value, CLL Society also recognized the importance of establishing a space explicitly for individuals who are still untreated.



## EDUCATIONAL PROGRAMS

Our educational programs are a primary means through which we connect patients and caregivers to top healthcare providers in CLL to present the latest treatment and care management information. To accommodate those unable to attend the programs live or who wish to review the material again, each educational event is recorded and provided as on-demand content on the CLL Society website.

This year, we explored expanding one of our educational events beyond its traditional webinar format to bring our community the information in a manner that would serve a variety of learning styles. From the **Playing CLL/SLL Chess: Planning Your Therapy Moves** webinar developed in partnership with the National Association for Continuing Education (NACE), we created a “Deep Dive into Five” podcast and webcast to condense the most salient points made during this 90-minute webinar into 20-minutes.

Just as important as educating patients and caregivers, CLL Society is proud to collaborate with our partner organizations to bring CLL education to healthcare professionals. We firmly believe that by providing educational learning opportunities to healthcare professionals, expert care will reach more patients.

**98%**  
of attendees rated  
the program as  
**‘Excellent’ or ‘Good’**

**11**  
live  
educational  
events hosted

**8**  
partnered educational  
events for healthcare  
providers



### Ask Me Anything Facebook Live Series

Feedback we consistently receive following all educational programs is that attendees wish more time was allocated to answering audience questions.

In response, we created our “Ask Me Anything” Facebook Live series. These events, live streamed over Facebook, are hosted by a CLL expert healthcare provider and a CLL/SLL patient advocate and entirely devoted to audience Q&A. Based on the overwhelmingly positive response from the two events held in 2022, we look forward to incorporating more of these events into our educational program going forward.

# EXPERT ACCESS™ PROGRAM

CLL Society's Expert Access™ Program continues to connect 120 patients annually with CLL to expert healthcare providers, offering individuals a no-cost second opinion consultation, personalized review of their health records, and answers to their questions in a one-on-one virtual environment.

# 89%

of participants stated they would make a change or take follow-up action regarding their care management plan following their consultation

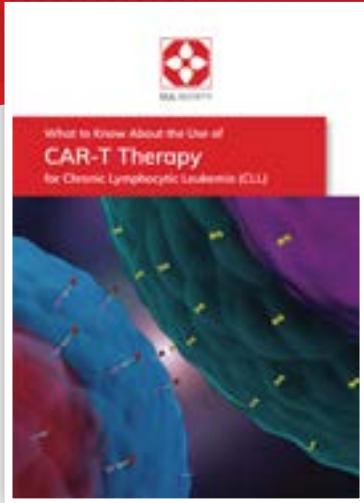


**1,652**  
responses to  
patient and  
caregiver questions

## ASK THE EXPERTS

Our Ask the Experts program continues to grow, offering those impacted by a diagnosis of CLL/SLL the opportunity to submit questions and receive a personalized response over email about their cancer. Over the year, CLL Society responded to over twice as many questions as were submitted the year before.





## CAR-T BROCHURE

CAR-T therapy is a revolutionary therapy and while the results for patients can be amazing, the science behind CAR-T can be somewhat complicated and advanced. To increase comprehension of this therapy as a viable experimental treatment option among those living with CLL, we developed an easy-to-understand CAR-T brochure for patients and caregivers.

**1,500+**  
individuals accessed  
the CAR-T Brochure



## PATIENT INSIGHT REPORT



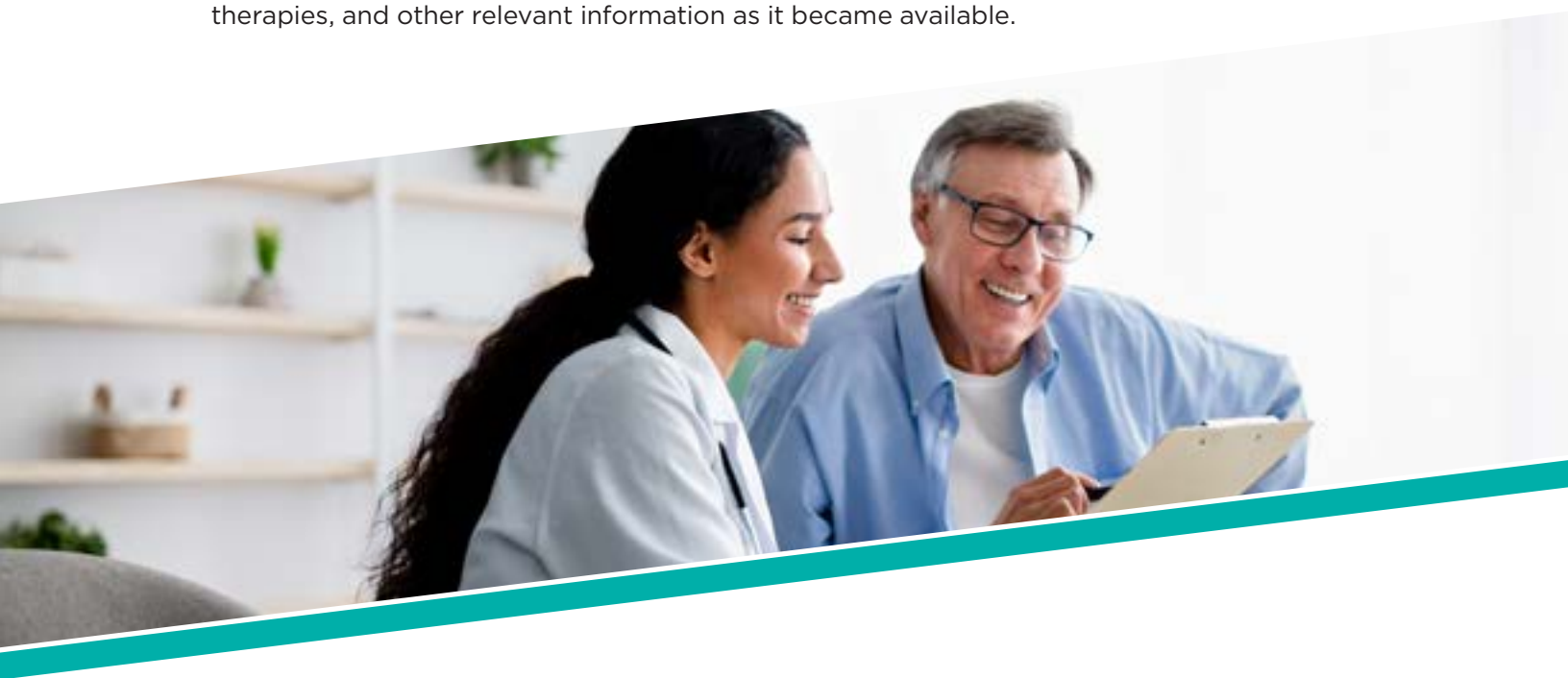
Throughout the year, we actively seek feedback from patients, caregivers, advocates, and others who engage in our services to assess the value they gain from our programming. In 2022, we took a new approach to analyzing post-program survey responses, synthesizing data from all our programs into our Patient Insight Report. This report presents us with a holistic understanding of our community's views of our services and the findings are being utilized to direct our 2023 content and program development.



# COVID-19 INFORMATION FOR PATIENTS AND CAREGIVERS

Despite the fact that multiple therapies for COVID-19 were developed in 2021 and 2022 specifically to protect vulnerable immunocompromised and other high-risk individuals, it was not always easy for those in need to receive them.

Throughout the year, CLL Society worked diligently to fill our website with a wealth of articles and statements our community could use in advocating to receive these COVID-19 therapies and to ensure quick and easy access to the most recent health guidelines, therapies, and other relevant information as it became available.



## COVID-19 Weekly Updates



In November 2022 we began producing weekly COVID-19 update reports due to the decreasing volume of media coverage and reliable up-to-date information on COVID-19.

These weekly updates were targeted towards providing pertinent information to those living with CLL/SLL on topics such as the rates of infection and community spread, current and emerging COVID-19 variants of concern, and the latest prevention and treatment options. While the rest of the world seemingly began to move on from COVID-19 precautions, CLL Society remained steadfast in protecting our community, recognizing their increased risk of severe disease progression if they became infected with COVID-19.



# POLICY & ADVOCACY

For the betterment of our community, we broadened and intensified policy and advocacy efforts to advocate in support of policies and legislation that would increase access to healthcare and improve health outcomes for patients with CLL and SLL.



# IMMUNOCOMPROMISED ADVOCACY

One of our most gratifying advocacy accomplishments in the year was the realization of an initiative that began in 2021, the International COVID-19 Blood Cancer Coalition (ICBCC), a multi-stakeholder coalition CLL Society played an instrumental role in establishing, with a mission to address the specific impacts of the COVID-19 pandemic on immunocompromised blood cancer patients. In February 2022, the coalition released its Joint Patient Impact Statement, which outlined recommendations for government and health authorities to protect immunocompromised blood cancer patients from COVID-19. Following the release of the statement, a widespread global social media campaign to raise public awareness was conducted.

When urging government officials to consider the immunocompromised community in decisions regarding COVID-19, CLL Society engaged our patient and caregiver community in two letter-writing campaigns that highlighted personal experiences and perspectives of those who would be directly impacted by policy changes. We also collaborated with fellow patient advocacy organizations, clinical societies, and coalitions through signing-on to various advocacy letters on issues of importance to our community, effectively bringing the needs of our community to the attention of government officials and pressing for measures to be taken on matters that directly impact the well-being of the CLL/SLL community.



## Changing the Definition of ‘Immunocompromised’

After working relentlessly for over a year, 2022 saw a big win for our advocacy efforts with the definition of ‘immunocompromised’ changed first by the National Institutes of Health (NIH), then followed by the U.S. Food and Drug Administration (FDA) and the Center for Disease Control (CDC), to explicitly include individuals with hematological malignancies regardless of current treatment status and specifically listed chronic lymphocytic leukemia patients. This change brought about an important shift in healthcare that made life-saving pre-exposure prophylactics and treatments for COVID-19 more readily accessible to our vulnerable patient population.



# SUPPORTING ACCESS TO QUALITY HEALTHCARE AND LIFE-SAVING THERAPIES



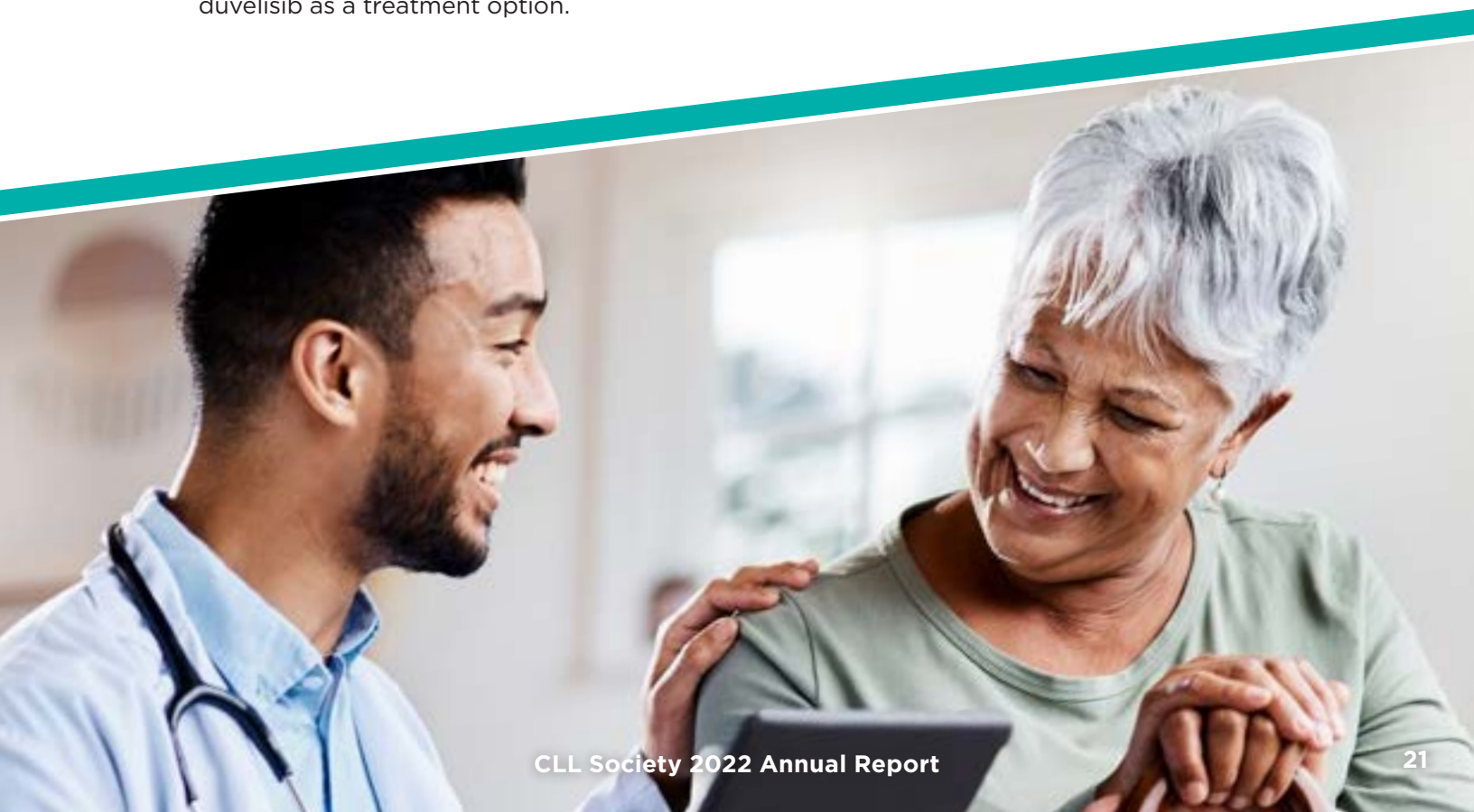
For the first time, CLL Society extended our advocacy and policy focus beyond COVID-19 to engage in additional policy matters important to our community in 2022. Recognizing the power of collective action, we joined multiple coalitions whose policy priorities were in line with our own.

## Supporting Access to Treatment Options

One of the largest unmet needs for those living with CLL/SLL is the limited therapy options available beyond the two FDA approved drug classes. In 2022, CLL Society presented at two Oncologic Drugs Advisory Committee (ODAC) meetings in support of the drug class PI3K inhibitors being a continued treatment option for CLL/SLL. In addition, we mobilized our community to submit well over 100 comments to the FDA, emphasizing the importance of preserving the specific PI3K inhibitor duvelisib as a treatment option.

## Supporting Innovation in Drug Development

In April 2022, Dr. Brian Koffman, CLL Society's executive vice president and chief medical officer was personally invited to speak at the Congressional Personalized Medicine Caucus's briefing titled "Promoting Innovation and Delivery of Cell and Gene Therapies". Dr. Koffman emphasized the importance of educating patients and healthcare providers about emerging cellular therapy options, including CAR-T, and advocated for continued innovation in the CAR-T field with the ultimate goal of it becoming another approved treatment option for patients with CLL.





# CLL SOCIETY RESEARCH PROGRAM

The CLL Society Research Program is a monumental milestone in advancing the organization's mission to improve the lives of those impacted by chronic lymphocytic leukemia/small lymphocytic lymphoma and marks our transformative commitment to solving unmet complications of the disease.



# FUNDING RESEARCH ON THE BIOLOGY OF CLL



CLL Society's Research Program was built in response to the notion of CLL being seen as a 'solved problem' in the academic and research field and the increasing challenge for researchers to secure adequate funds for CLL-specific research. The program is devoted to supporting underfunded bench and translational science exclusively in areas specific to CLL/SLL, with a focus on promoting pre-clinical research that addresses four defined critical areas of unmet need.

- 1 Disease progression after receiving both a B-cell receptor inhibitor and venetoclax (double refractory disease)**
- 2 Richter's transformation**
- 3 The need to strengthen or reconstitute the impaired immune system**
- 4 Curative therapies**

The CLL Society Research Program was established with the Young Investigator Award targeting junior faculty members and postdoctoral fellows. This award aims to develop the next generation of laboratory scientists who will be committed to solving the unmet needs of patients with CLL/SLL and advancing treatment options in this disease.





**We are proud to stand out among blood cancer organizations as one of the only organizations whose research program is solely dedicated to funding CLL/SLL research. As our funding capacity grows, we aim to provide more research grant opportunities in CLL/SLL, further contributing to enhancing patient lives and the pursuit of a cure.**

## 2022 Young Investigator Award

CLL Society awarded its inaugural Young Investigator Award to Dr. Christine Ryan of Dana-Farber Cancer Institute in Boston. Dr. Ryan is a senior hematology/oncology fellow specializing in CLL/SLL and lymphomas. She is currently mentored by Dr. Matthew Davids, a member of CLL Society's Medical Advisory Board.

Dr. Ryan's research project, titled **BH3 Profiling to Identify Novel Vulnerabilities in Richter's Syndrome**, focuses on Richter's Syndrome (also called Richter's Transformation), a serious complication in CLL which currently carries a poor prognosis for patients.



*I just want to say how incredibly honored and grateful I am to receive this Young Investigator Award from CLL Society. I was just so excited when I heard the news and I am incredibly excited about the support for this research project. I am just very passionate about this particular area within CLL and SLL and I think that this award will really provide important support for our efforts to make advancements in the treatment of Richter's [syndrome]. Thank you to the CLL Society.*

**- Christine Ryan, MD**





# DIVERSITY, EQUITY, AND INCLUSION

CLL Society was founded with the aspiration of being an inclusive support system for all individuals impacted by chronic lymphocytic leukemia/small lymphocytic lymphoma. Our ongoing diversity, equity, and inclusion efforts affirm our dedication to fostering a welcoming environment where everyone can access the unique resources they need.



# CLL SOCIETY'S COMMITMENT TO DIVERSITY, EQUITY AND INCLUSION

*At CLL Society, we believe all individuals impacted by chronic lymphocytic leukemia/small lymphocytic lymphoma (CLL/SLL) deserve equitable access to quality education, support, and care. We believe that an individual's race, ethnicity, gender, sexual orientation, religion, disability status, age, geographic location, veteran status, or other underrepresented identities should not result in any barriers to accessing quality healthcare and support resources. We believe that only when patients and caregivers touched by CLL/SLL from all types of diverse backgrounds and identities feel welcome and valued can our mission to address the unmet needs of this community be achieved.*

*Among our staff, board of directors, and advisory boards, we continually work to promote a culture where everyone's voice is included and valued equally. We believe embracing our differences strengthens our ability to be innovative thinkers in the pursuit of understanding and meeting the unmet needs of people impacted by CLL/SLL. We are committed to learning and growing together so we may improve the lives of all those living with CLL/SLL.*





## Understanding Genetic Factors in CLL

Although the incidence of CLL is lower among African Americans than among Caucasians, age-adjusted survival is inferior. In 2022, Mayo Clinic received funding from the National Institutes of Health (NIH) for a non-interventional study to determine genetic factors related to African Americans with CLL, which has sparsely been studied before. CLL Society was proud to partner with Mayo to provide resources and assist with accrual of African American CLL patients to this important study.

## BIPOC Resources Webpage



With the new website, we established a dedicated BIPOC (Black, Indigenous, People of Color) Resources webpage in recognition of the importance of offering a variety of resources tailored to meet diverse needs. This page houses medical abstracts on the variations in CLL/SLL development and disease course among different racial and ethnic groups and on issues of equitable access to care, lists organizations offering specialized services for minority and underrepresented groups, and shares information on the importance of diversity in clinical trials.

## AccessiBe for Website Accessibility

In 2022, we engaged with the web accessibility platform accessiBe to enhance the CLL Society website, optimizing it for individuals with diverse needs through customizable visual adjustments and advanced features that allow those with visual and motor impairments to navigate the website with ease.



## Spanish Educational Resource

In partnership with Bag It Cancer, CLL Society worked to translate our free educational resource bag for patients and caregivers into Spanish. Especially for those newly diagnosed, this valuable resource provides a comprehensive overview of CLL/SLL biology, treatment options, care management, survivorship, emotional impacts of cancer, diet and nutrition, and much more.





# FINDING FUTURE PATHWAYS

In 2022, we took monumental steps toward creating a brighter future for patients and their loved ones impacted by a diagnosis of chronic lymphocytic leukemia/small lymphocytic lymphoma. Alongside our achievements, we actively worked toward new initiatives aimed at furthering our mission and vision.



## COMMUNITY HEMATOLOGIST OUTREACH PROJECT

Limited access to expert healthcare remains one of the largest, persistent barriers to improving health outcomes for patients, as the relatively low incidence of CLL/SLL can result in community hematologists lacking extensive knowledge about the latest treatment options.

To address this issue, CLL Society has developed plans for a Community Hematologist Outreach Project. Through this initiative, we intend to position ourselves as a trusted source of expert information for patients, caregivers, and healthcare professionals in the community healthcare setting, and bring better care to patients.



## EXPANDING RESEARCH GRANT OPPORTUNITIES

The CLL Society Research Program launched in 2022 with a single grant opportunity. The intention from the start has always been to offer more grants to researchers as funding capacity grew. In 2023, CLL Society established plans to add a Career Development Award and Integrative Medicine in CLL Award for the 2024 Research Program grant cycle.



# ONLINE PATIENT AND CAREGIVER LEARNING MODULES



Over the years we have utilized a variety of channels to provide the CLL/SLL community with quality, physician-curated education, including patient-friendly reviews of medical abstracts, interviews with expert CLL healthcare providers, and online educational webinars. Recognizing that individuals have different learning style preferences, we have begun translating our most essential educational content into dynamic online learning modules.



## CLL SOCIETY POLICY INSTITUTE

CLL Society is dedicated to expanding our policy and advocacy efforts in the pursuit of improving health outcomes and equity for patients with CLL/SLL. We are proud to report that our policy and advocacy efforts were officially formalized at the beginning of 2023 with the launch of the CLL Society Policy Institute. We are excited about the future successes and impacts this new initiative will bring.



# INDUSTRY PARTNERS

CLL Society is incredibly grateful to have the support of numerous industry partners who believe in the vital education and support we provide for those impacted by CLL/SLL along their care journey.

## The Industry Advisory Council

The Industry Advisory Council (IAC) is comprised of companies committed to advancing initiatives for the CLL community. CLL Society is grateful for the following 2022 IAC Members.

### Platinum Members



### Silver Members



## Additional Supporters

AbbVie

Adaptive

Ascentage

AstraZeneca

BeiGene

BMS

CSL Behring

Genentech

Janssen/ Pharmacyclics

Lilly

MEI Pharma

Merck

Regeneron

SecuraBio

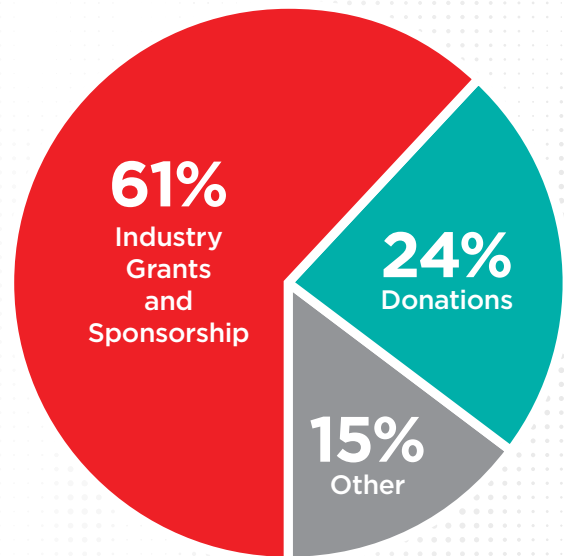
## Special Thanks to Our 2022 COVID-19 Sponsors

CLL Society would like to thank **Regeneron**, **Pharmacyclics**, and **Janssen** for supporting our ongoing efforts to bring CLL/SLL patients and caregivers the latest information on COVID-19 in 2022.

# 2022 FINANCIALS

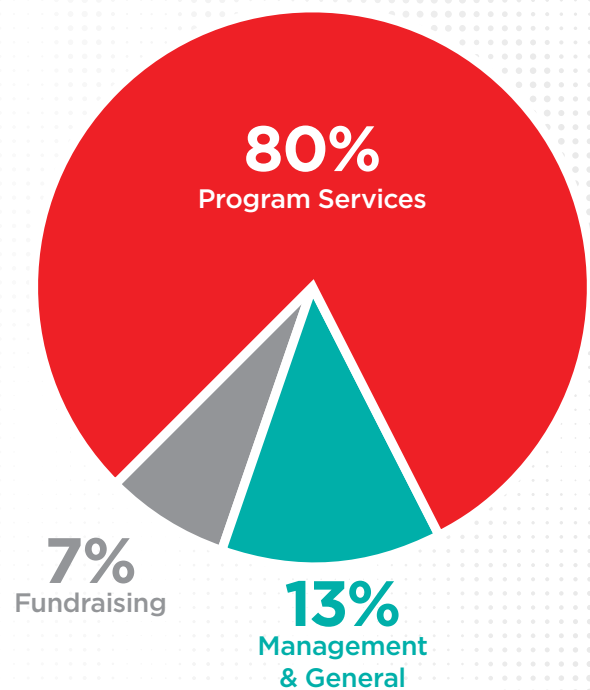
## Revenue

Industry Grants and Sponsorship	\$1,611,033	61%
Donations	\$619,918	24%
Other	\$401,449	15%
<b>TOTAL</b>	<b>\$2,632,400</b>	



## Expenses

Program Services	\$1,664,663	80%
Management & General	\$265,228	13%
Fundraising	\$145,490	7%
<b>TOTAL</b>	<b>\$2,075,351</b>	



# BUILDING NEW PATHWAYS TOGETHER

A better future for those impacted by chronic lymphocytic leukemia/small lymphocytic lymphoma cannot be achieved without the dedicated support of our community. We are grateful for the various ways in which our community rallies together to raise vital funds in support of CLL Society's mission.

## Giving Tuesday

For a second consecutive year, CLL Society was honored to have the unwavering support of our community on Giving Tuesday. We continue to be astounded by the generosity demonstrated on this special global day of giving. This year's campaign raised \$107,503. We extend our gratitude to every individual who contributed to the campaign and stood alongside us in our mission to enhance the well-being of all individuals living with CLL/SLL.



## Celebrating Long Lives Inaugural 5K Walk and Run

In 2022, CLL Society implemented its first-ever fundraising event, Celebrating Long Lives 5K, as a way to provide our community with an opportunity to actively engage in fundraising efforts. Participation in the event offers individuals the chance to not only raise awareness within their own network of CLL/SLL, but also empowers them to invite others to join them in supporting a cause that holds personal significance. The inaugural event, held virtually, garnered participation from 328 individuals across the country and around the world and raised \$55,917 for the mission of CLL Society.





## Rhonda France

Rhonda, whose diagnosis of CLL 9 years ago came as a surprise, has found CLL Society to be a valuable source of information along her journey. Joined by her husband Kirk and friends, she was the top fundraiser during the Celebrating Long Lives 5K event, raising an impressive \$7,906 in support of CLL Society's mission.

"I considered it a privilege to participate in the Celebrating Long Lives 5K and raise funds for CLL Society. This Society adds much value to those on the CLL/SLL journey as we walk/run this route. I am humbled and grateful to all the friends and family who donated in support of this group. Look forward to Celebrating Long Lives together again in the future."



## Neil Muchin

Neil participated in the Celebrating Long Lives 5K with his wife, Andrea Muchin, and brother, TJ Mates-Muchin, pictured to the left. Doing so allowed him to give back to the organization that has supported him in navigating his diagnosis of CLL. We are grateful for his efforts that resulted in him surpassing his goal and bringing in \$5,963 for fellow patients and caregivers.

"I was so happy to participate in the inaugural Celebrating Long Lives 5K and raise money for CLL Society. CLL Society is an invaluable resource for those with CLL (and SLL) as we manage through the many intricacies of CLL. It's wonderful to have an organization advocating for CLL patients as well as the immunocompromised.

This was particularly true over the last years of living through the pandemic. The generosity of my family and friends helped me to surpass my original fundraising goal. Looking forward to participating next year!"



# DONOR ACKNOWLEDGMENTS



## In Memory of Thomas Henry

In February of 2022, CLL Society lost a friend, advocate, and scholar to COVID-19. Tom Henry, a pharmacist and CLL patient, gave his time and expertise generously to CLL Society and the CLL/SLL community as a whole. For CLL Society, he was active for many years supporting our work writing articles with his pharmacy expertise, conducting patient-friendly reviews of medical abstracts from major hematology/oncology conferences, answering patient questions as part of CLL Society's Ask the Expert program, and guiding CLL Society's work through participation on our medical advisory board, and later expert medical council. He was always providing reassurance to fellow individuals with CLL/SLL, as he never took a break from caring for and counseling others. Tom Henry's passing was felt deeply by CLL Society, and he will be missed dearly by all those who knew him.

## Thank You to Our Donors

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, caregivers, 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 2022.\* 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.

## \$10,000+

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Anonymous: 3 donors  
Carroll Family Fund at Seattle Foundation

Dr. Brian and Patricia Koffman  
Vigyan Singhal

## \$5,000-\$9,999

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Linda B. Blackburn  
Diane Iorio  
Richard J. and Laura A. Malnight

Barbara and Howard Massey  
Charles Newman  
Arthur Schneider

## \$1,000-\$4,999

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Anonymous: 10 donors  
John Aldrich  
Michael Allemang  
Donald Armenia  
Paul Barbehenn  
Stacy Barber  
Urs Bauder  
Janis Benach  
Lois Benedetti  
Matthew Berry  
John Bethell  
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Julie Hess  
Douglas A. Himes  
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James Horne  
John and Shari Howerton

## \$1,000–\$4,999 (Continued)

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Hannah Jarson  
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Jonathan Khuner  
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William Kyburz  
Laurence Lannom  
Eileen Letts  
Kathy Levi  
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Peter Vitulli  
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Patricia Ann Wallace  
Holly Watson-Evans  
Steve Winfield  
Harvey Yavil  
Doug and Lynette Zezoff  
Robert and Wanda Zimmer  
Lucia Zimmitti

## \$500–\$999

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Anonymous: 7 donors  
Leigh and Jon Anderson  
Mitch Austin  
Joel Bacon  
Robert A. Barton  
Jim Beenders  
Lynne Berry  
Robert C. Bjorke

Paul Blackmer  
Lindsay Blanton, JR  
Carolyn Burton  
Nancy Byers-Teague  
Ron Campbell  
D. L. Carangelo  
Dr. Bertrand and Lois Chenard  
John and Lisa Christenson

## \$500-\$999 (Continued)

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Cheryl and Michael Coirin  
Susan Conrad-Kanstul  
Jennifer Creager  
Matthew S. Davids, MD  
Stephen and Cindy Delesie  
Debra Demos  
Lauren Densmore  
Michelle Echelberry  
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David Snow  
Karen Soltis  
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Michael Touloupas  
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Judith Vertalka  
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Nancy Wagman  
Karen Wald  
Patricia Wall  
Thomas Wisnowski  
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 our Development and Communications Manager, Nicole Kamphuis, at [nkamphuis@cllsociety.org](mailto:nkamphuis@cllsociety.org) for a resolution. An up-to-date 2022 donor recognition page can be found on our website.*



# TESTIMONIALS



*The Expert Access Program is invaluable. This “Pay it Forward” service by these amazing expert health care providers without a doubt is saving lives, helping many of us gain back our life and assisting to empower us with knowledge. I LOVE this program and am humbled by the doctors that give of themselves to provide it.*

**~ Barbara Schulz, CLL Patient, Arizona**



*CLL Society is a great organization with exceptional leadership that works hard to deliver the best care for the CLL patient. The organization empowers patients and caregivers with outstanding resources to help them to make the best decisions on how to move forward with medical care. CLL Society can truly help to alleviate the fear of being diagnosed with leukemia.*

**~ Mike Keene, CLL Patient, Wisconsin**



*My consultation with a CLL specialist through CLL Society's Expert Access Program was a smooth, professional, caring process that exceeded my expectations at every turn. Responses to my advance questions were provided almost before I asked them. The physician brought to our consultation a quality of expertise, communication and responsiveness to my questions that cannot be overstated. I consider this consultation to have been a great privilege; I am very grateful for it; and it has given me energizing confidence for the path ahead.*

**~ Ann Ludwig, CLL Patient, Maryland**



*I am a CLL patient, and the CLL Society has been a critical resource to help me better understand my disease and potential treatment options.*

**~ Donald Donnelly, CLL Patient, New Jersey**



*I was diagnosed with CLL in June 2020. Your organization's website, webinars, etc. have given my wife and I the valuable resources and support we need to understand and learn about all the treatment options after the Watch and Wait stage, which is where I am currently. Your website is easy to navigate and provides a wealth of knowledge and support at a time when a patient and caregiver need it the most. Thank you!*

**~ Anthony De Rosa, CLL Patient, New York**



# CLL SOCIETY

## SMART PATIENTS GET SMART CARE™

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[support@cllsociety.org](mailto:support@cllsociety.org)

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CLL Society by visiting:

