






strong voices

2020 ANNUAL REPORT

CLL SOCIETY

Listing to the

strong voices

of the Chronic Lymphocytic Leukemia community

An estimated 178,000 individuals in the United States are living with chronic lymphocytic leukemia/small lymphocytic lymphoma, and approximately 20,000 people are newly diagnosed with CLL each year.
The development of novel therapies over the past several years has revolutionized care and significantly improved outcomes for those with CLL. However, problems and challenges persist. CLL remains incurable, patients continue to be at higher risk for secondary cancers and serious infections including COVID-19, and there is evidence showing many patients are not receiving the full benefit of breakthroughs in treatment. CLL Society is dedicated to addressing these issues and empowering patients with the information and support they need to navigate the rapidly evolving treatment landscape so they can advocate for their best care. As our motto states: Smart Patients Get Smart Care™.

In 2020, we listened to the **strong voices** of those living with CLL every day, those providing healthcare for CLL/SLL patients every day, those researching better treatment options for CLL every day, and those advocating for the needs of CLL/SLL patients and caregivers every day to provide the best services we could to the CLL community across the United States and beyond.

powerful words

Never stifle a cancer patient’s voice
Never ignore a question

Let our voices be

When CLL/SLL patients are newly diagnosed, their immediate questions are big, daunting questions of life and death.

But later, more specific, pointed questions move to the forefront, such as: Where do I begin to secure the best possible care for my CLL? What treatments are available? Do they work? Who is qualified to credibly guide me?

That is where hope begins.

How do we know this? We’ve lived it.

> When Brian was diagnosed in 2005, there was no one-stop-shop to find reliable physician-curated up-to-date patient-friendly information on the latest CLL research, but we suspected there must be kindred souls out there.

As we launched the singular voice of Brian’s blog, endless unanswered questions and immeasurable patient need became unearthed.

At first, we had simply wanted the best possible care for Brian’s CLL. But as we witnessed the need, we became determined to create a non-profit that would function as a conduit for critical support and the best, most credible, cutting-edge treatment information for all CLL patients and their caregivers, so that one wouldn’t need to be a doctor to get the best possible care.

Our little 501(c)(3) was established late in 2013 from our kitchen table with the money we loaned it, and we set about giving volume to the questions and concerns of CLL patients and their caregivers.

2013 was a banner year! New treatments were quickly improving patient outcomes, confirming that the biology of CLL had been cracked. We committed to following the science!

We launched the CLL Society website in a flurry of new writing and borrowing from Brian’s blog. With shameless audacity we registered as press to attend the major blood cancer conferences where we recorded video interviews with CLL experts, then dutifully unpacked the content to make the information understandable and helpful to patients and caregivers. We searched and selected the most important abstracts, published research, and explained its relevance in patient friendly terms.

Over the ensuing years, moving toward 2020, the CLL Society put down roots deep into the CLL patient and caregiver community and grew its programs and services in response to our patients’ expressed needs.

Our patient surveys blossomed into published research presented at the major conferences, letting the professional community know what really matters to their CLL patients.

When the COVID-19 pandemic posed a threat to our immune-suppressed community CLL Society was ahead of the curve, moving all meetings, webinars, forums, and support groups to virtual settings and emphasizing the importance of wearing masks and social distancing long before others recognized the importance.

Today, the voice of the CLL Society is taken seriously by the professional hematology community.

Next year, we will be funding young researchers to help find answers to unsolved problems in CLL such as how to improve our compromised immunity. At the same time, we will be building the next generation of CLL physician/scientists.

Founders Statement

strong

Thank you to the early and still giving generous individual donors who saw CLL Society's potential, and to the expert medical community who welcomed and supported CLL Society from day one, recognizing that we were fulfilling huge unmet needs for their patients.

Thank you to the pharmaceutical industry who supported our nascent charity's programs and services.

Thank you to our fellow CLL patients and caregivers who stepped up and volunteered to give forward by helping to establish and lead almost 40 CLL-specific support groups across the USA and Canada. And thank you to the patients and caregivers who take part in our support groups, completing our surveys and offering the kindness, knowledge, and support that only a real live CLL patient can believably share with another.

Help us to connect with and support those who don't yet know us, so that everyone enjoys the benefit of expert care, such as those in rural locations, those in communities of color, and other underrepresented groups, so that we can help in derailing CLL from shortening anyone's life.

Thank you to our strong and committed Board of Directors, Medical Advisory Board, Expert Medical Council, Patient Advisory Board, Industry Advisory Council and CLL Society Staff.

None of this would be possible without you.

Let's revisit our goals: We wanted the best possible care for Brian's CLL, and we founded the CLL Society because we also wanted every CLL patient and caregiver to be able to access that same critical support and cutting-edge treatment information to secure their own best care.

Both dreams have come true.

The CLL Society is rock-solid and invested in your long life.

Be well.

Smart Patients Get Smart Care™

Brian Koffman,
MDCM (retired), MSEd
Co-Founder
CLL Society

Patricia Koffman
Co-Founder
CLL Society

Patricia Koffman

Message from the Executive Director

Dear Friends

The year 2020 was filled with many unexpected challenges.

We rang in the new year filled with excitement, eager to serve our CLL/SLL community in new and meaningful ways. We never could have anticipated the changes that were about to transpire. By early March, we realized that the COVID-19 pandemic required an immediate and agile response. CLL Society quickly took action to suspend all live events and in-person Support Group meetings to protect our community members from risk during a period in which much about the virus remained unknown.

> At the same time, we recognized that CLL/SLL patients and caregivers were in need of information and education, perhaps like never before. Reflecting on this time, we are immensely grateful for the medical experts, patient and caregiver volunteers, staff, industry partners, and generous donors who all supported CLL Society in these efforts.

This support allowed us to quickly change course and respond to the urgent needs of our community in virtual settings. We are deeply saddened by the loss of life and other negative impacts our CLL Society friends have suffered in the wake of this pandemic, and we are determined to continue advocating to protect the immunocompromised patient population from the threat of further harm. With tenacious effort and continued support from our incredible community, we are hopeful that these goals will be achieved.

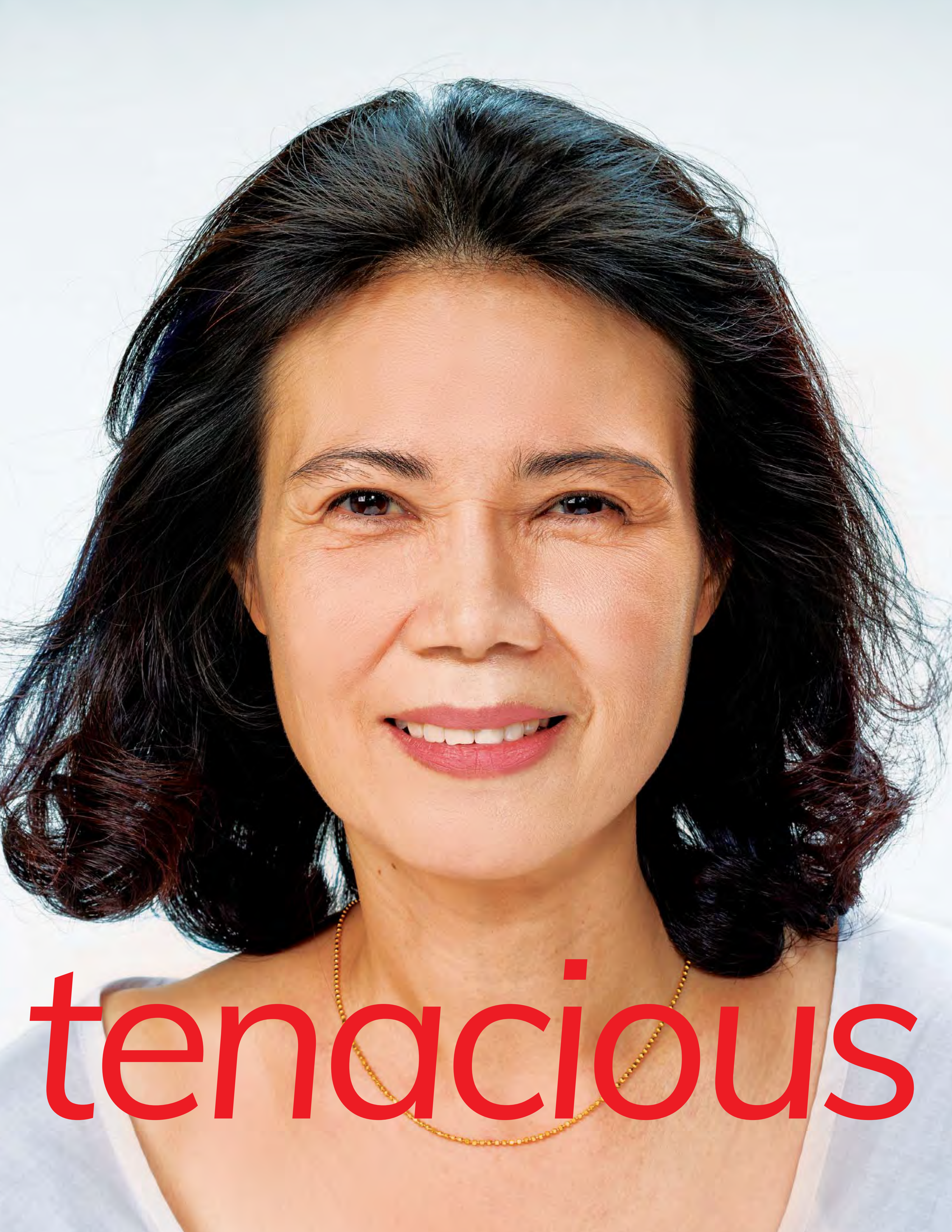
This was also a year of renewed activism to advance racial equality and social justice. Inspired by the global movement and understanding the responsibility businesses and organizations have to set the tone we wish to see reflected throughout our world, CLL Society took its first steps on what will be an ongoing journey to examine our internal culture and define our commitment to diversity, equity, and inclusion. We developed a comprehensive improvement plan and rewrote our mission and vision statements to better emphasize the inclusive environment we wish to create. We want our message to be clear: CLL Society exists to serve all CLL patients, and we want to help overcome barriers so that all CLL patients get the best possible care. We recognize that complex social systems have reinforced disparities and injustice, and that these problems will not be solved overnight. We look forward to working with, and listening to the strong voices of our entire community to continuously improve and contribute to meaningful solutions.

Despite the significant challenges 2020 presented us, I am pleased to report that CLL Society has risen to those challenges and advanced as an organization. We adopted a five-year strategic plan, which established a strong vision for our future. We began work on redesigning our website, with the aim to reach a larger audience and to create a more user-friendly experience for those who come to us seeking support and information. And we ended the year in a stronger financial position than ever before, which will allow us to expand and improve the programs and services we provide to those living with CLL. Challenges will continue beyond 2020. CLL Society is committed to being here for many years to come, continuing to work toward our ultimate vision of an entire CLL community that can equitably access quality healthcare, education, support, and lead healthier and richer lives.

Your investment in the long life of CLL Society is an affirmation of the difference our work makes for those impacted by CLL. Thank you for being a part of the CLL Society.

With gratitude,

Carly Boos, MEd, MBA
Executive Director


tenacious

Mission Statement

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

Vision Statement

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

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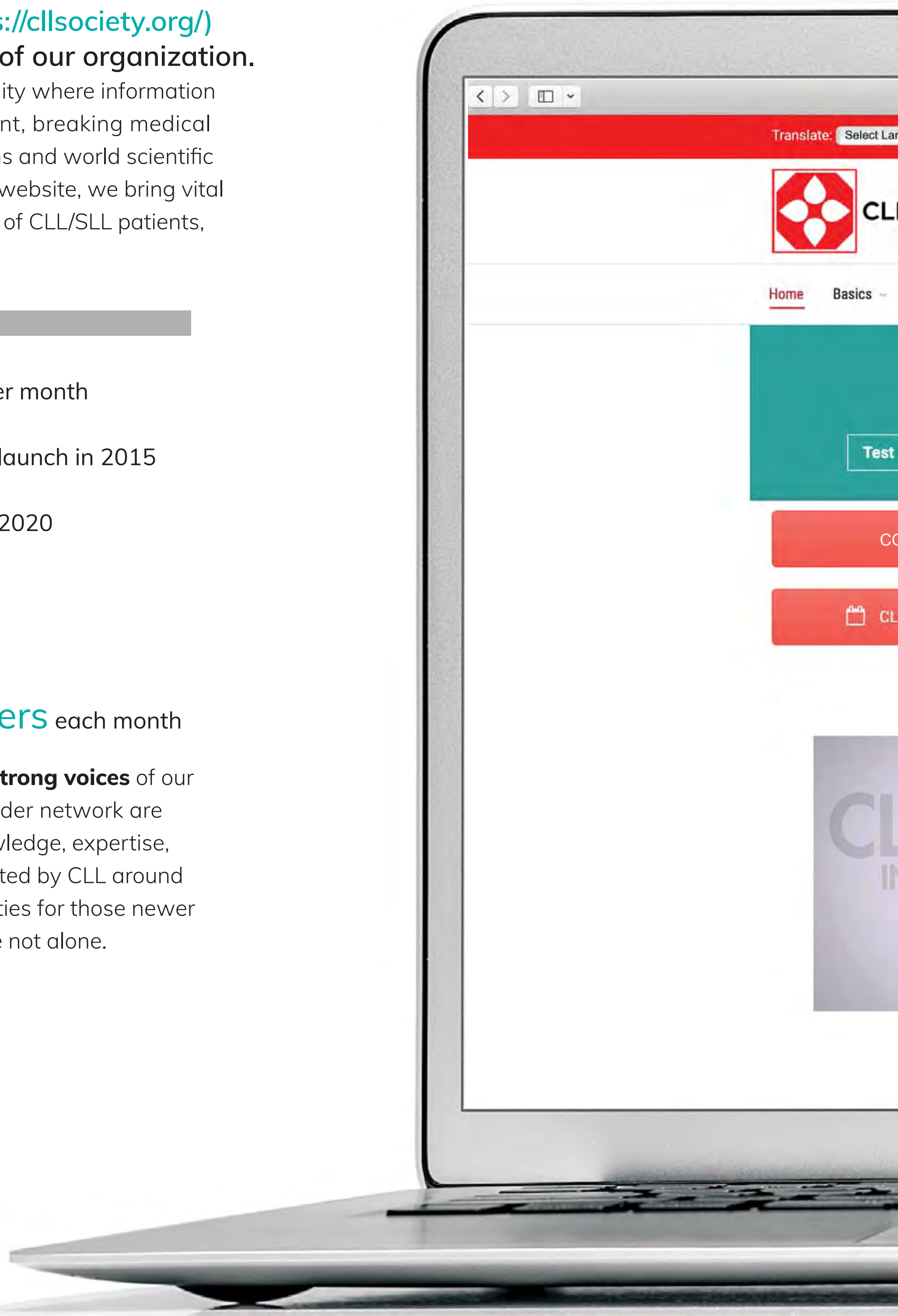
The CLL Society
Website

Our vital voice growing to reach all impacted by CLL

The CLL Society website (https://cllsociety.org/) has always been a focal point of our organization. It is a vast resource hub for our community where information on treatment options, care management, breaking medical developments from research publications and world scientific conferences can be found. Through our website, we bring vital information and support into the homes of CLL/SLL patients, caregivers, and supporters everywhere.



FACTS

Average 70,000+ page views per month

2 million+ page views since its launch in 2015

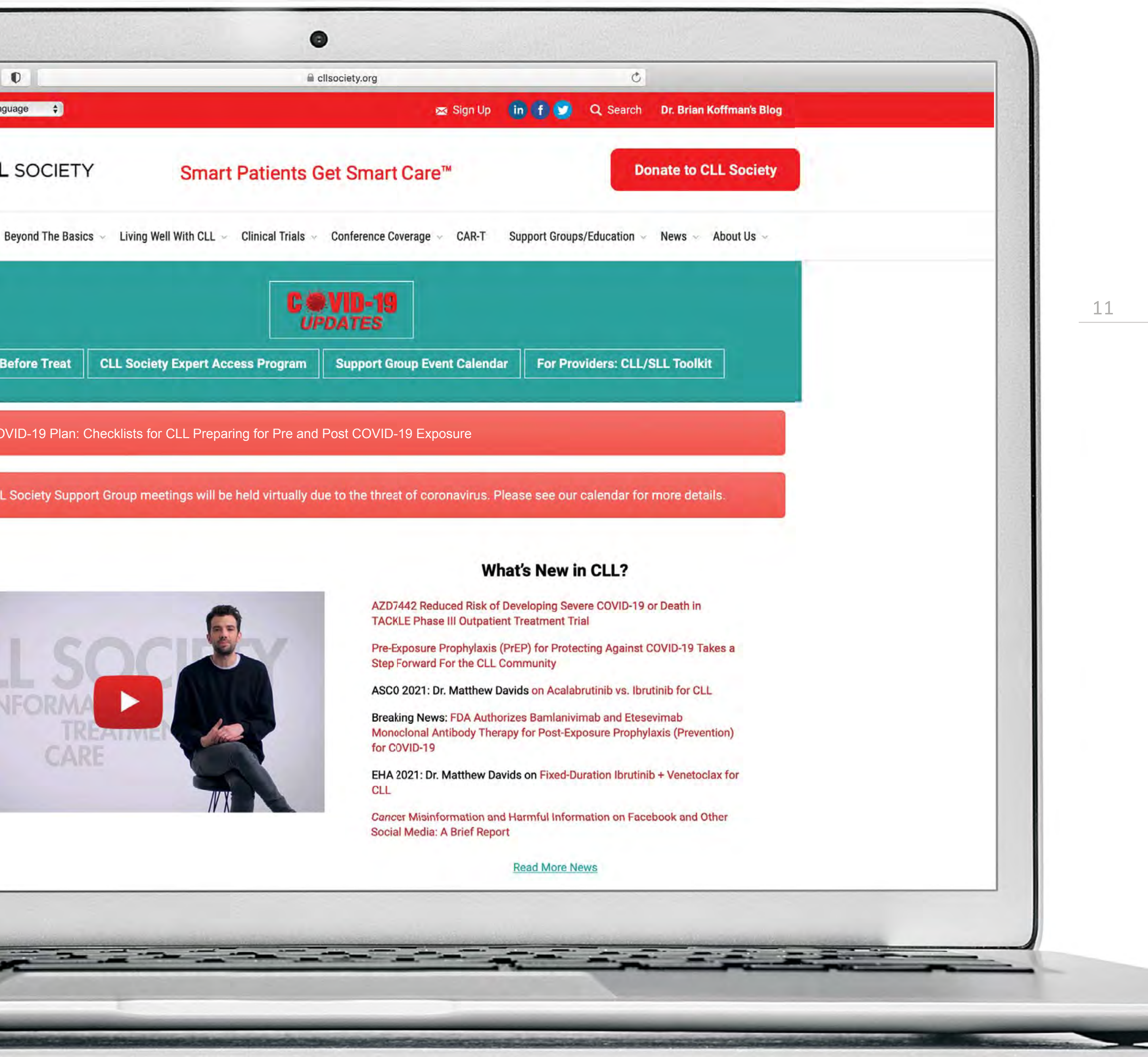
Total of 849,921 page views in 2020

1,641 pages of content

338 video interviews

Average 27,000 unique users each month

Our website is also a space where the **strong voices** of our patient, caregiver, and healthcare provider network are shared. Our community carries the knowledge, expertise, and experience to comfort others impacted by CLL around the globe. They offer learning opportunities for those newer to the disease and assure them they are not alone.



OVID-19 Plan: Checklists for CLL Preparing for Pre and Post COVID-19 Exposure

L Society Support Group meetings will be held virtually due to the threat of coronavirus. Please see our calendar for more details.

What's New in CLL?

AZD7442 Reduced Risk of Developing Severe COVID-19 or Death in TACKLE Phase III Outpatient Treatment Trial

Pre-Exposure Prophylaxis (PrEP) for Protecting Against COVID-19 Takes a Step Forward For the CLL Community

ASCO 2021: Dr. Matthew Davids on Acalabrutinib vs. Ibrutinib for CLL

Breaking News: FDA Authorizes Bamlanivimab and Etesevimab Monoclonal Antibody Therapy for Post-Exposure Prophylaxis (Prevention) for COVID-19

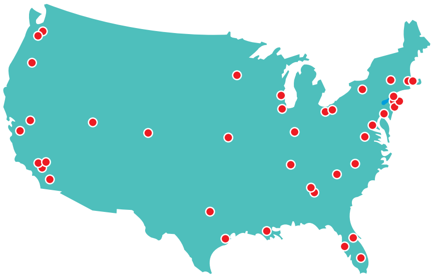
EHA 2021: Dr. Matthew Davids on Fixed-Duration Ibrutinib + Venetoclax for CLL

Cancer Misinformation and Harmful Information on Facebook and Other Social Media: A Brief Report

CLL Society Support Groups bolster community

Out of a desire to improve patients' support systems, CLL Society established a network of support groups across the nation. Traditionally these support groups provide an in-person element that fosters the development of deep connections and support systems. However, the COVID-19 pandemic forced us to pivot in March and transition all our patient support groups to an online platform beginning April 2020. This was an important transition to make, not only to protect the health and well-being of the more than 1,800 individuals involved, but to allow this critical support network to persist during a time of increased hardship.

Led by dedicated, CLL Society-trained volunteer facilitators, these groups are a safe place for individuals to share their experiences, anxieties, concerns, and learn more about their disease together. In isolation, a patient's world is small. Our Support Groups provide a focused forum for individuals to connect with one another, and where each **strong voice** can be heard.



FACTS

5 new Support Groups established

36 Support Groups across the United States

2 Support Groups in Canada

91% of people surveyed feel more supported by a new network of friends

87% of people surveyed are more comfortable with their diagnosis

Strong Voices

“ I joined our group when it was founded in 2016 and have been participating ever since. The CLL Society Support Group in the D.C.-Maryland-Virginia area has been such a great resource whenever we have been facing treatment decisions and simply to socialize with others on this CLL journey. This amazing and resilient group has been an inspiration to me in understanding how people can live joyfully and thrive regardless of a cancer diagnosis. ”

Debra Linick
Virginia
Caregiver to a loved one with CLL since 2011

“ I have been a member and co-facilitator of the San Diego chapter of the CLL Society Support Group since April 2019. The CLL Society website, email alerts and monthly newsletter, the Bloodlines, provide groundbreaking scientific information for patients and caregivers, regarding treatments and other critical issues that affect our lives, most recently, COVID-19. During the meetings, it is good to hear the stories, thoughts, and concerns of other patients as we navigate this disease now and in the future. We all learn from the experiences of others and the Support Group forum, though virtual, helps us to share vital information that can improve or even save lives. The CLL Society Support Group and sponsored Educational Forums have enriched my life in many ways; knowledge and friendship are two of the most valuable assets I have gained through my membership and attendance.”

Therese Conlin
California
CLL Patient since 2011


impactful

"It has been a privilege to be a co-facilitator of the Raleigh Area CLL Society Support Group in 2020, serving many parts of North Carolina and even into Virginia. We have about 50 people on our email list, with monthly virtual meetings having about a dozen participants. The group generates great discussions, and the members value the education and information about current programs and CLL news, as well as a wealth of experience from several participants who have been CLL patients for a decade or more. As a facilitator, it is gratifying to have members note how specific discussions have helped them in their journey. As a patient, I also enjoy learning each month from the discussion, Bloodlines newsletters and CLL Society webinars."

Dan Patterson
North Carolina
CLL Patient since 2018

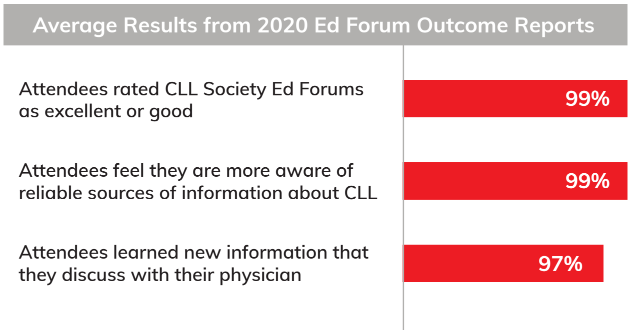
The CLL Society
Programs

Educational programs keep our community empowered with knowledge

No matter where a patient is in their journey, CLL Society's educational programs bring the **strong voices** of CLL expert medical professionals to those who need it most.

CLL Society Ed Forums

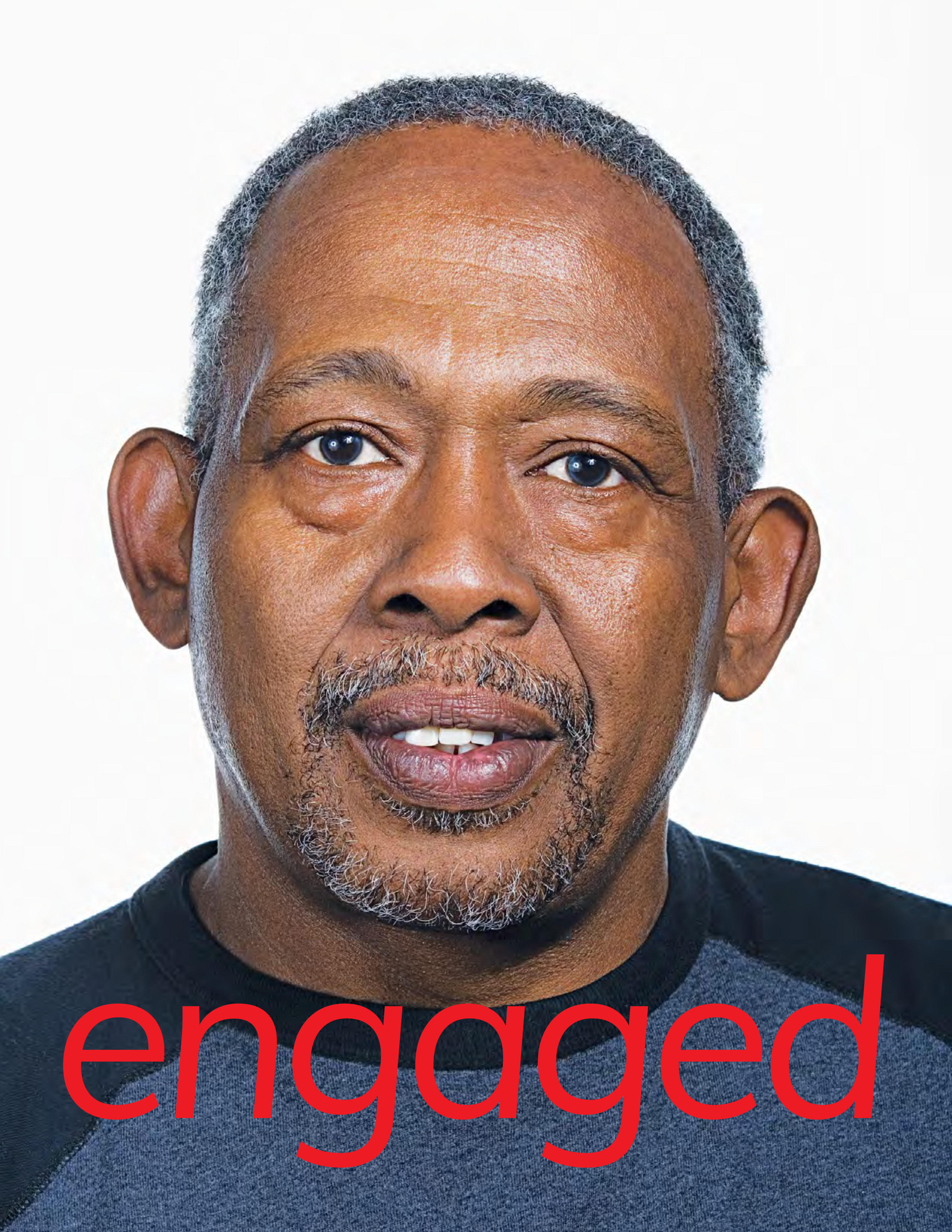
CLL Society Ed Forums have historically been hosted as live events in 12 cities across the United States each year. They bring the most recent and ground-breaking developments in CLL treatment directly to patients and their caregivers. In 2020, we held three Ed Forums before the COVID-19 pandemic made having the remaining nine planned events in-person infeasible. However, the **strong voices** of our community made clear the pressing need to construct a new Ed Forum adapted to a virtual environment. We listened, and in October of 2020 CLL Society's Global Virtual Patient & Caregiver Educational Forum featured the **strong voices** of 16 CLL experts and patient advocates. Bringing in 703 live virtual participants, this event served the largest number of patients and caregivers to date at a single Ed Forum. In combination with the three live events, our 2020 Ed Forums reached 984 individuals live.


Average Results from 2020 Ed Forum Outcome Reports

CLL Society Webinars

In 2020, CLL Society hosted three Webinars in our traditional format reaching 1,141 patients and caregivers. These Webinars are one-hour events where **strong voices** from the medical field present on a designated topic and answer questions from attendees. In March of 2020, we made the decision to create a new initiative, CLL Society COVID-19 Virtual Community Meetings. These town hall-style meetings were held in place of our traditional Webinars as a dedicated time to respond to the impacts of COVID-19 on our immunocompromised community. Through CLL Society COVID-19 Virtual Community Meetings, we serve as a **strong voice** to our community, providing guidance on navigating a global pandemic as a CLL/SLL patient.


Average Results from 2020 Webinar Outcome Reports



engaged

The CLL Society
Programs

Providing confidence in decision making

Expert Access™ Program

Research shows that having access to a CLL expert significantly improves health outcomes for a CLL/SLL patient. CLL Society's Expert Access™ Program was built on this principle and brings expert care into the homes of patients around the country.

FACTS

120 patient consultations completed in 2020

94% of people surveyed learned something new from their Expert Access™ physician

71% of people surveyed stated they would make a change or take follow-up action after their consultation

Through Expert Access™, we have become a **strong voice** for breaking down barriers to access in care such as health insurance and location. With Expert Access™, patients receive a no-cost second opinion from a healthcare professional who is an expert on CLL. Having confidence in a diagnosis and treatment plan through a second opinion assists patients in developing the **strong voice** they need for advocating to receive their best possible care.

Test Before Treat™

With the Test Before Treat™ Campaign, CLL Society aims to be a **strong voice** to our community, advocating for all patients to complete three vital tests (**FISH, IgHV and TP53**) before starting any treatment. Unfortunately, we know that all too often CLL/SLL patients do not receive the recommended minimal testing before starting treatment. This is especially true for patients starting second and subsequent treatments for their CLL.

FACTS

Over 4,500 page views of one-pager Test Before Treat™ information sheet

Over 3,000 downloads of one-pager Test Before Treat™ information sheet

2,000 Test Before Treat™ wristbands distributed as reminder

Only 58% of people surveyed understood what tests they needed before receiving treatment and why

As a part of this campaign, we developed a one-pager of information for patients and caregivers to download for use in developing personal knowledge and to inform their local healthcare providers. Through campaign efforts in 2020, we also distributed over 2,000 wristbands to our supporters to serve as a constant reminder of the importance of testing. As patients and caregivers around the nation spread this crucial information, they become a **strong voice** in the effort for all CLL/SLL patients to receive this essential testing.

Strong Voices

" I was diagnosed with CLL in June of 2014. Like most CLL patients, I was originally placed on watch and wait, but my cancer progressed aggressively. When I was first diagnosed, my white blood cell count was at 24,000 and seventeen months later, on the day I was told I had to start treatment, I was 350,000. I was prescribed FCR and, not knowing anything about genetic testing or targeted therapy, I followed the advice of my community hematologist and went ahead with treatment.

In hindsight, this was a mistake. The chemotherapy was brutally difficult, and my cancer did not respond well. I switched oncologists, underwent extensive genetic testing, and discovered my CLL was 17p deleted, had complex karyotype, and was unmutated. If I had known this information beforehand, I would not have undergone FCR therapy.

Luckily, I was quickly enrolled in a clinical trial and on Acalabrutnib monotherapy for almost four years and when I started to resist it, I was switched to another monotherapy, Ibrutinib. I have responded very well to both monotherapies. My CLL specialist watches my genetics and discusses my options early before they are needed.

I strongly believe that everyone should find a CLL specialist to have informative conversations and ensure that proper tests are completed before starting any treatment. The CLL Society is an invaluable resource to help you navigate throughout your journey by helping you stay informed and asking the right questions. I am personally very grateful to the CLL Society as I don't believe I would be where I am today without having found them. They definitely helped me become a Smart Patient.

Test Before Treat is not just a saying – it can literally save your life!"

Tammi Garrett
Ontario, Canada
CLL Patient since 2014

" This [Expert Access] Program is incredibly valuable, and I am more than grateful to the CLL Society for offering it! It confirmed things I had previously researched and brought to light things I didn't know re: my diagnostic test results. It also helped to narrow my focus while further researching treatment options.

I had a follow-up with my local oncologist and had extra confidence in my knowledge to ask all the right questions thanks in large part to my conversation with the physician I saw through the Expert Access Program. This was the best and most informative visit I've had with my oncologist so far. Thank you."

Suzy Kelly
Nevada
CLL Patient since 2018

Strong Voices

" My name is Barbara Massey, and I have CLL. My husband Howard has lymphoma, so we are both immune-compromised. Earlier this year CLL Society offered (at no cost) a couple of very nice KN95 masks to any CLL patient who requested them. Masks are necessary for both of us, and we were happy to receive this protection from COVID-19!

I have been fortunate to be a member of CLL Society from the beginning. These masks symbolize to me how dedicated CLL Society is to educating, protecting and advocating for those of us with CLL. I know that I can look to CLL Society to stay up to date on CLL treatments and clinical trials, plus I can learn how we immune-compromised patients can stay safe during the pandemic!

CLL Society helps me be the smartest and most well- informed CLL patient that I can be, and I am grateful!"

Barbara and Howard Massey
California
CLL Patient since 2006

Our unwavering support in the face of uncertainty

The COVID-19 pandemic took a toll on everyone in 2020. But for our immuno-compromised community, the pandemic has heightened consequences. We knew that in these especially hard times we had to become a **strong voice** for our community on managing COVID-19 and CLL.

COVID-19 Webpage

In March of 2020, we launched our COVID-19 webpage (https://cllsociety.org/covid-19/) and received 110,000 page views by the end of the year. This webpage has become an archive of information and resources on COVID-19 as the pandemic has developed over time. One resource we developed early on that has proved particularly useful to patients in effectively leveraging their **strong voice** to advocate for their needs is CLL Society's Official Statements. Patients and caregivers use these statements in conversations with their healthcare providers to communicate their increased vulnerability to COVID-19 and higher risk of complications.

KN95 Mask Distribution

As the COVID-19 pandemic progressed throughout 2020, the need for increased protection for CLL/SLL patients became crucial. CLL Society took action to do our part in helping protect the CLL community and distributed over 2,000 KN95 masks to patients in need in November 2020.

CLL Society COVID-19 Virtual Community Meetings

CLL Society COVID-19 Virtual Community Meetings began in March 2020 as a space for patients and caregivers to come together in discussion with healthcare professionals. These meetings offer an opportunity for individuals to share their experiences and apprehensions to develop a unified **strong voice** advocating for their unique needs.

FACTS

110,000 total page views in the year since launch

3 official statements were issued in 2020 on COVID-19 and CLL/SLL patients

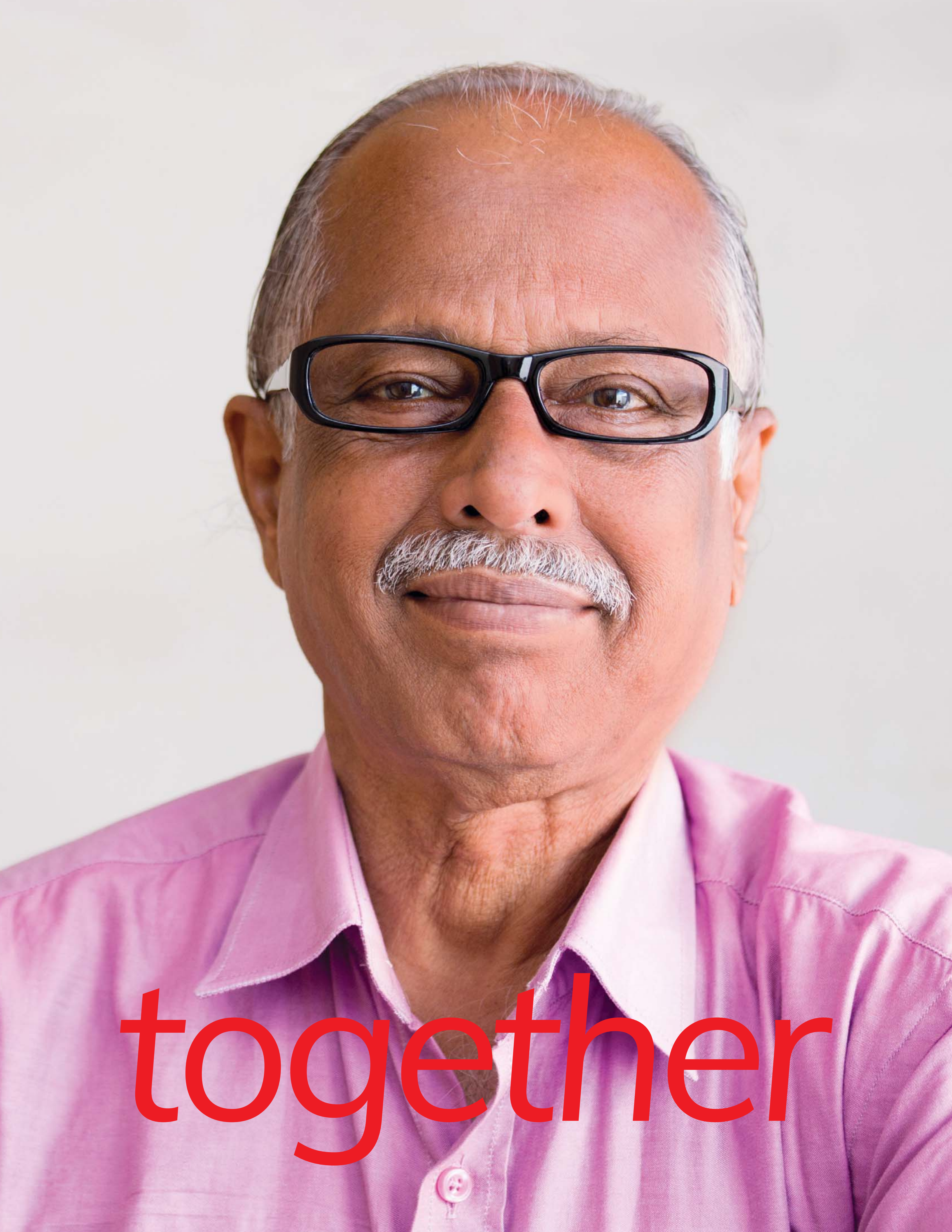
Receiving a total of 6,900 downloads across all statements

2,000 KN95 Masks distributed to patients in November 2020

4 Virtual Community Meetings held in 2020 with 5,129 total participants

Over 75% of people surveyed indicated they feared becoming critically ill with COVID-19 due to CLL

With a total of 5,129 live virtual participants across the four meetings held in 2020, we tackled issues of COVID-19 testing, how to manage CLL treatment during the pandemic, the potential effectiveness a vaccine could have for CLL/SLL patients, risk of transmission in various forms, best practices with masks, and much more. These meetings have proven that in a community, shared experiences strengthen individual voices and bring about increased understanding of collective concerns.


together

Looking forward

In 2020, CLL Society created our Strategic Plan, looking forward to the next five-year period of 2021-2025.

In our Strategic Plan, we committed to continual improvement and expansion of the support we provide for CLL/SLL patients and caregivers, and plans to be a catalyst for change within the greater CLL environment, to ensure everyone living with CLL can access their best possible care. We acknowledge that change does not happen on its own but is a product of multiple actors coming together and advocating for better access and outcomes. CLL Society is dedicated to being a **strong voice** of change and a lasting actor in CLL/SLL patients' journey with the disease. With your support, we are here to stay.

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Joined Staff August 2021

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Restructured September 2021

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Dan Patterson
Patient

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Patient

Haleh Simi
Patient

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Patient

Wayne Wells
Patient

Bruce Wright
Patient

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Deborah Sims
Patient
Melbourne, Australia

Nick York
Patient
United Kingdom

2020 Industry partners

CLL Society is grateful to have the support of the following companies who serve as **strong voices** in the medical development field and believe in the difference we make for the CLL community.

pharmacyclics®
An AbbVie Company

Adaptive
biotechnologies™

Bristol Myers Squibb™

FOUNDATION
MEDICINE®

Verastem
Oncology

AstraZeneca

NOVARTIS

TG Therapeutics

Genentech
A Member of the Roche Group

abbvie

janssen
PHARMACEUTICAL COMPANIES OF
Johnson & Johnson

Strong Voices

" This is just a brief note about the important impact my CLL Society Expert Access physician had on my treatment for CLL. They were kind enough to review my medical records and chat with me about my condition and possible treatments. Although they said I appeared to be a decent candidate for FCR treatment, they pointed out that I had not had the IGVH test. They said those results would be key to making a final decision about treatment. Our interview was especially timely because I was scheduled to begin FCR as prescribed by my local small-town oncologist. After we chatted, I called my doctor's office and requested the test. As it turned out, I was the first patient for whom he had ever prescribed this test.

Patients shouldn't be embarrassed to use the program because they think they might offend their doctors. It can be confirmation that you are getting the correct care, or as it was in my case, a red flag to include additional important tests before making final treatment decisions. Either way, the patient is the winner.

A patient should also do his or her best to find an oncologist whose chief areas of interest include blood malignancies. This was impressed upon me in my interview, and the physician was correct. It's not always easy to do, and this doctor might not become the primary oncologist, but a patient should at least have someone on his team to whom he can refer the most important treatment questions. This, I think, is one of the points of the Expert Access Program: it's the first step for getting input from a specialist to confirm that you are getting the best, most up-to-date care.

Finally, I really would like to tell new patients not to lose their minds if they are in watch and wait. I wish I was still in watch and wait. They are in a great position to become educated and gather all the facts about CLL and its treatments. The Expert Access Program is a wonderful opportunity to begin this process.

I believe this program played a key early roll in my journey with CLL, and want you to know the crucial, positive impact you have had in my life."

David Klausmeyer
Maine
CLL Patient since 2019

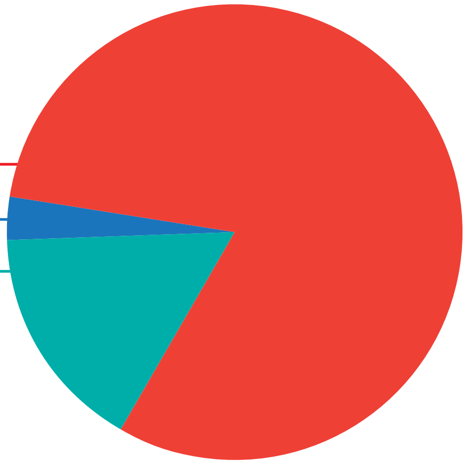
The CLL Society

Financials

CLL Society 2020 Expenses

$1,225,926

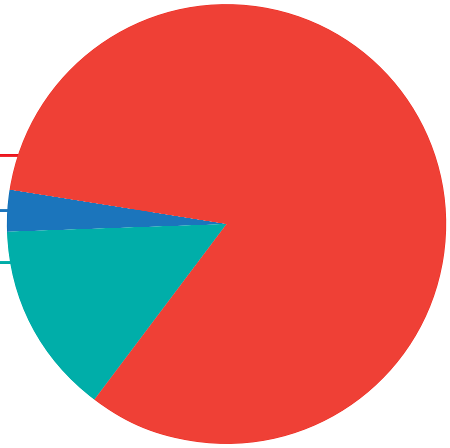
Program Services	$996,282	81%
Fundraising	$35,615	3%
Administration	$194,029	16%



CLL Society 2020 Revenues

$2,250,782

Industry Grants and Sponsorship	$1,862,900	83%
Other	$59,100	3%
Donations	$328,782	14%



The CLL Society

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Our heartfelt thank you

We are sincerely grateful for the individuals, foundations, and corporations who invested in us so that we could invest in the long lives of CLL/SLL patients. We would not be able to do our work without your generous contributions. Thank you.

Acknowledged below are the names of individuals who donated $500 or more and provided consent to be listed*. 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.

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