

“

We are hoping to increase access to optimal care in order improve outcomes and the overall quality of life for patients with CLL/SLL.

## NCCN Awards Grants to Improve Care for Patients With Chronic Lymphocytic Leukemia/Small Lymphocytic Lymphoma

The NCCN ORP has announced the awarding of new quality improvement research grants aimed at advancing care for patients with Chronic Lymphocytic Leukemia/Small Lymphocytic Lymphoma (CLL/SLL). The NCCN ORP will oversee these projects, with funding provided through support from AstraZeneca.

CLL/SLL is the most commonly diagnosed form of leukemia in the United States, with approximately 20,000 new cases reported annually.<sup>1</sup> Many individuals, especially older adults, face significant challenges in receiving optimal treatment. The goal of these projects is to explore ways to close any gaps in care delivery, improve quality of life, and address disparities in treatment.

“Despite advances in treatment, many patients with CLL/SLL, particularly those from underserved communities, are not receiving care that aligns with current clinical guidelines. We are hoping to increase access to optimal care in order improve outcomes and the overall quality of life for these patients,” explained Crystal S. Denlinger, MD, Chief Executive Officer, NCCN. “We congratulate these researchers and look forward to seeing their contributions make a tangible difference in future care for patients with CLL/SLL.”

The selected projects are:

- Larry Cripe, MD, Indiana University Melvin and Bren Simon Comprehensive Cancer Center
  - The CLL/SLL Care Road Map: Accessible, Flexible, and Interactive Web Enabled Resources for High Quality Treatment Decisions
- Alessandra Ferrajoli, MD, The University of Texas MD Anderson Cancer Center
  - Improving the Detection of Other Cancers in Patients With Chronic Lymphocytic Leukemia Using Multicancer Early Detection Testing
- Sara Tinsley-Vance, PhD, APRN, Moffitt Cancer Center
  - Predictors of Health-Related Quality of Life in Adults With Chronic Lymphocytic Leukemia or Small Lymphocytic Lymphoma

“We are delighted to support NCCN ORP in new research initiatives for patients afflicted by CLL/SLL,” said Alan Yong, MD, US Medical Affairs Franchise Head Hematology, AstraZeneca. “Despite many advancements in treatments impacting patient outcomes over the past 10 years, CLL/SLL is still considered incurable. Research focused on optimizing diagnostics, treatment decisions, and improving quality of life are thus very important for patients.”

Proposals were peer-reviewed by a Scientific Review Committee comprised of leading oncologists and experts in hematologic malignancies from NCCN Member Institutions.

The NCCN ORP fosters innovation and knowledge discovery that improve the lives of people with cancer and supports preclinical, translational, and clinical research and quality improvement projects in oncology at NCCN Member Institutions. In an effort to improve collaboration in cancer research, the NCCN ORP also maintains a shared resources website, an informed consent database, and points to consider on the best practices for biorepositories, registries, and databases. For more information, visit [NCCN.org/orp](https://www.nccn.org/orp).

---

### Reference

1. Siegel RL, Miller KD, Fuchs HE, Jemal A. Cancer statistics, 2022. *CA Cancer J Clin* 2022;72:7–33.
- 

## NCCN Hosts Patient Advocacy Summit on Improving Access to Accurate Health Information

On December 6, 2024, NCCN hosted a Patient Advocacy Summit in Washington, DC. The annual event brings together leading experts to promote strategies and best practices for improving

cancer care. This year's summit focused on practice and policy solutions for sharing accurate, evidence-based health information with patients and caregivers. It featured a keynote address from W. Kimryn Rathmell, MD, PhD, MMHC, Director of the National Cancer Institute (NCI), along with panel discussions that included Robin Vanderpool, DrPH, Chief of the NCI's Health Communication and Informatics Research Branch.

"When people with cancer are empowered to make informed choices about their care, they tend to have better outcomes," said Crystal S. Denlinger, MD, Chief Executive Officer, NCCN, who welcomed attendees at the start of the program. "That means we must provide patients with clear, trustworthy information that meets them where they are. For example, the NCCN Guidelines for Patients offer plain-language explanations of the latest evidence-based recommendations. They feature expert guidance on most cancer types, along with prevention, screening, and supportive care. We share them in multiple languages and formats, including books and webinars."

"Every person facing cancer needs and deserves high-quality information to understand their options and guide their decisions. The NCI, NCCN, and other organizations represented at the summit contribute to a complex information landscape to meet the needs of people with cancer," said Dr. Rathmell. "Trust in the cancer research enterprise is essential to ensuring that scientific progress includes and reflects the diversity of patient experiences and providing reliable health information is a key aspect of earning and honoring that trust."

During a series of Best Practices Presentations for sharing patient-centered health information, NCCN's Senior Director of Patient Information Operations, Dorothy Shead, explained that the NCCN Guidelines for Patients are available for free at [NCCN.org/patientguidelines](https://www.nccn.org/patientguidelines) or via the NCCN Patient Guides for Cancer App—thanks to funding via the NCCN Foundation.

Additional presentations came from spokespersons for We Engage 4 Health, HPV Cancers Alliance, Cancer Support Community, and the Frontier & Rural Patient Navigators at the University of Utah Huntsman Cancer Institute. More information can be found in a new resource toolkit at [NCCN.org/patient-advocacy-resources](https://www.nccn.org/patient-advocacy-resources).

## Preventing the Spread of Misinformation

Speakers underscored the need to identify and debunk any myths that can create misunderstanding and a false sense of security. They discussed the importance of working with trusted messengers to counter misinformation.

"A key lesson learned from COVID-19 was the importance of having trusted professional and community advocates address misinformation and disinformation," noted Martha Dawson, DNP, RN, FAAN, FACHE, Immediate Past President, National Black Nurses Association. "Diverse researchers, scientists, policymakers, faith-based leaders, and community advocates with similar lived experiences can serve as sources of trusted information. It is important to support and expand cancer education at the community level and engage with people where they are born, live, work, play, worship, and transition life."

"Misinformation in cancer care can create confusion, delay treatment, and undermine trust between patients and providers. By addressing these challenges head-on, we can empower patients with accurate, accessible information to make informed decisions about their health," agreed Skyler Johnson, MD, Professor, Department of Radiation Oncology, Huntsman Cancer Institute at the University of Utah. "Effective communication is at the heart of quality cancer care. We need to equip clinicians and patients with the tools and strategies to counter misinformation, foster trust, and work together through an increasingly complex health care landscape."

## Clear and Consistent Messaging to Build Trust

A recurring theme throughout the discussions was the importance of clear and consistent health messaging that is delivered in a way everyone can understand. That means keeping in mind inclusive technology and supportive health literacy levels. Speakers cautioned against using too much medical jargon, instead focusing on language that can resonate. They also noted that it can be hard to retain information right after learning you or a loved one has cancer, so careful repetition can be key.

Speakers also reiterated how crucial it is to build trust with each patient through open and honest two-way relationships.

“  
We need to equip clinicians and patients with the tools and strategies to counter misinformation, foster trust, and work together through an increasingly complex health care landscape.”

*(cont. on next page)*

“As a survivor and caregiver, I’ve seen firsthand the impact that clear and culturally relevant care discussions can have for patients and their families,” explained Randi Ervin, Survivor/Advocate, Pancreatic Cancer Action Network (PanCAN). “Compassionate, empathetic, and relatable communication—delivered at the right time—can make a difficult journey feel a little more manageable for families like mine.”

Bryce Reeve, PhD, Professor, Population Health Sciences, Duke University School of Medicine, commented: “As a health care system, we have a responsibility to ensure that every individual with cancer has a voice in their care. This is especially important for young children and individuals from marginalized communities whose values, perceptions, and experiences have often been overlooked.”

“Regardless of our affiliations, whether it be community health care, academic medicine, the federal government, or the nonprofit sector, it is critical for us to recognize the richness of collaborating with non-science/health care community members to address challenges such as health misinformation and equitable clinical trial participation,” concluded Arnethea Sutton, PhD, Interim Assistant Director of Community Outreach and Engagement, VCU Massey Comprehensive Cancer Center. “Not only will these collaborations contribute to trust-building amongst all partners, but the richness of diverse thought and perspectives will contribute to the translation of science and ultimately equitable outcomes for all.”

Learn more about past NCCN Oncology Policy Summits, and save-the-date for future events, at [NCCN.org/summits](https://www.nccn.org/summits). Next year’s series will include the topics: Primary Care and Oncology Collaboration, Artificial Intelligence, and Unique Needs of Veterans and First Responders.



National Comprehensive  
Cancer Network®

## NCCN Virtual Reimbursement Resource Room

Learn about patient assistance and reimbursement programs available.

### Search by:

- Cancer Type or Supportive Care Indication
- Drug Name
- Reimbursement Program



**NCCN**  
REIMBURSEMENT  
RESOURCE

**Access for FREE online or via the app!**  
**[NCCN.org/reimbursement](https://www.nccn.org/reimbursement)**