

# Advancing Regional Care for Patients With Chronic Lymphocytic Leukemia

## Spotlight on Oregon Health & Science University

### Knight Cancer Institute

Although chronic lymphocytic leukemia is the most common form of leukemia in adults and accounts for one quarter of new leukemia cases annually,<sup>1</sup> compared with other cancers, this disease is rare. In 2023, approximately 18 740 new cases of chronic lymphocytic leukemia will be diagnosed—often in community care settings—which may not have the multidisciplinary expertise available to support treatment and long-term care.

In 2020, the Association of Community Cancer Centers (ACCC) set out to examine the incidence rates and geographic location of chronic lymphocytic leukemia diagnoses across the country in relation to regional access to institutions with specialization for treating chronic lymphocytic leukemia. Through the development of heat maps,<sup>2</sup> which revealed the

areas in the US most in need of expertise, an opportunity emerged in 2022 to identify and understand specific state and regional challenges to access, as well as identify solutions to provide equitable access to care for this patient population.

In part with ACCC's education program, A Regional Approach to Advancing Care in Chronic Lymphocytic Leukemia, with support by AstraZeneca, Janssen Oncology, and Pharmacyclics, ACCC explores how cancer programs are utilizing community outreach and other support strategies to improve care for underserved populations diagnosed with chronic lymphocytic leukemia. In this spotlight, ACCC shares Oregon Health & Science University (OHSU) Knight Cancer Institute's approach to advancing care for patients with chronic lymphocytic leukemia.

#### **Knight Cancer Institute – Oregon Health & Science University**

**Location:** Portland, Oregon

**Center Type:** Academic Medical Center



#### **OSHU Knight Cancer Institute**

The Knight Cancer Institute is a research institute and academic medical center in Oregon that provides surgical, medical, and radiation oncology services across seven locations in the Portland metropolitan area. The institute is the only National Cancer Institute (NCI)–designated comprehensive care center located between Seattle and Sacramento and maintains collaborative relationships with several other community cancer programs in the state.

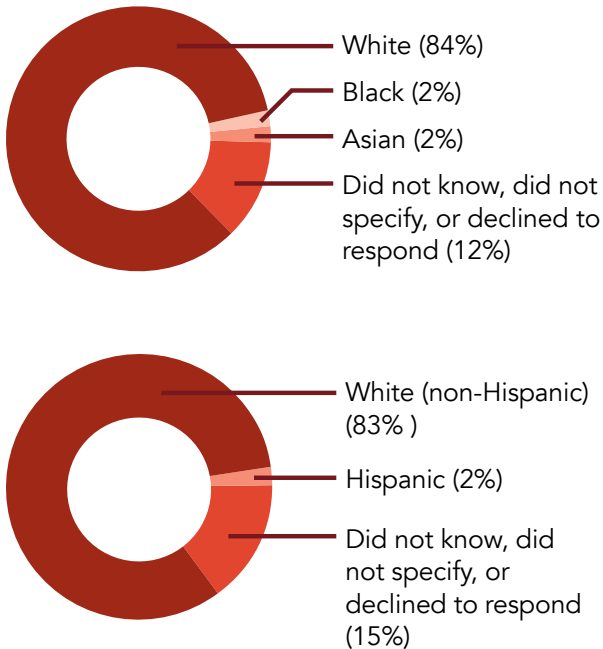
Led by cancer research pioneer Brian Druker, MD, and director of the OSHU Knight Cancer Institute, whose groundbreaking

research in leukemia helped develop imatinib (Gleevec)—the first medication that specifically targets cancer cells—the institute is a national leader in cancer research and in early detection cancer screening. In 2022, the OSHU Knight Cancer Institute treated over 5400 patients with cancer, managed 236 adult stem cell transplants, and administered 50 chimeric antigen receptor (CAR) T-cell therapy treatments. Under the leadership of Stephen Spurgeon, MD, professor and director of the chronic lymphocytic leukemia program, the institute has approximately 65 newly diagnosed patients with chronic lymphocytic leukemia under its care.

## Patient Profile

At the OSHU Knight Cancer Institute, the median age of patients with chronic lymphocytic leukemia is 67 years. In 2022, approximately 52% of this patient population identified as male and 48% as female, a ratio that has been relatively consistent according to the institute's data for previous years.

### Patients with chronic lymphocytic leukemia identified their race and ethnicity as:



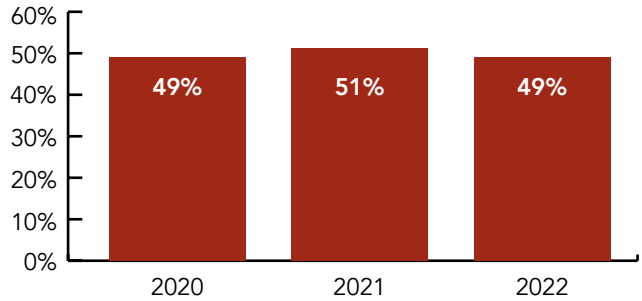
This data generally aligns with the state of Oregon's US Census population demographics.<sup>3</sup> Although Spanish and Russian are spoken by less than 5% of its patients, nearly all patients (98%) prefer to speak English.

In 2022, approximately 68% of patients with chronic lymphocytic leukemia had commercial insurance coverage for their care (eg, Blue Cross, Managed Care, or other commercial), 15% were covered through Medicare, and 11% were covered through Medicaid.

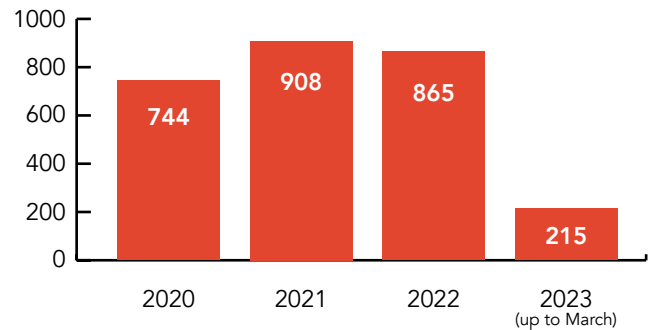
Since 2020, the OSHU Knight Cancer Institute has received 197 new chronic lymphocytic leukemia patient referrals—an average of 53 unique patient referrals per year.

OSHU Knight Cancer Institute's treatment rates for patients with chronic lymphocytic leukemia are highlighted below:

### Yearly referral conversion rates with follow-ups established in clinic and/or infusion services:

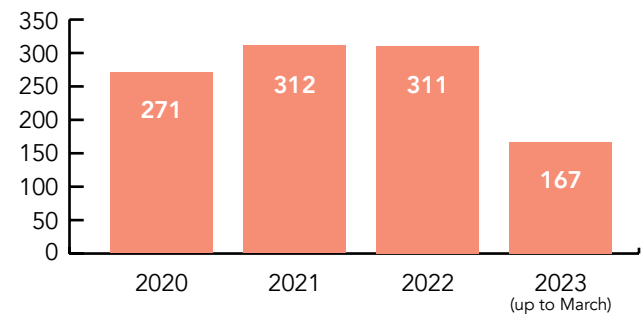


### Number of returning visits:



**Total returning visits January 2020 to March 2023: 2732**

### Total unique patients:



## Addressing Regional Challenges

According to the NCI, residents living in rural areas experience significant health inequities due to limited access to quality healthcare, shortages of primary care physicians and oncologists, limited to no insurance coverage, persistent poverty, food insecurity and higher rates of poor nutrition, and a score of socioeconomic disparities which place

them at higher risk of cancer and other chronic diseases.<sup>4</sup> In Oregon, 12.2% of people are uninsured, 7.5% of families are living below poverty, and 20.3% are living below 150% of poverty, according to NCI state cancer profiles.<sup>5</sup> These disparities have led the Oregon Health Authority to set a strategic goal to “eliminate health inequities in Oregon by 2030.”<sup>6</sup>

From a geographic perspective, 90% of patients referred to the OSHU Knight Cancer Institute with chronic lymphocytic leukemia reside in Oregon or in the Metro Portland area, which reaches into Washington state. About 50% of the in-state adult patient population live within OHSU’s vast geographic catchment area, which spans 36 counties. This means over 50% of its patients travel more than 25 miles to receive cancer services. As Oregon is a primarily rural state with dangerous mountain passes, particularly during the winter, this distance creates unique regional challenges for patients, particularly older and frailer patients with chronic lymphocytic leukemia.

For patients at the OSHU Knight Cancer Institute, transportation, distance, food insecurity, and health literacy are the primary barriers to care and the institute offers multiple support services to address these barriers through its Patient and Family Services program. Because chronic lymphocytic leukemia affects older adults, caregiver support (to help ensure treatment adherence and to monitor adverse effects) and financial difficulties with co-pays and out-of-pocket expenses also present significant challenges.

To address these barriers and the psychosocial needs of its patients, Patient and Family Services includes a team of 20 oncology specialized social workers (including a director and manager) who work in collaboration with the institute’s comprehensive patient navigation program. This team utilizes a distress screening tool (a modified version of the Edmonton Symptom Assessment System, which includes nutrition and rehab questions as well as the PHQ-9 to assess for depression) for all patients to complete prior to their first follow-up visit. This screening includes comprehensive questions about a patient’s family, finances, transportation, nutrition, and other issues. The distress screening also includes a specific malnutrition screen and social workers collaborate closely with dietitians to address patient nutrition. The institute maintains a Patient Emergency Assistance Fund—approximately \$80,000 per

year in emergency assistance—and is primarily utilized to provide transportation, lodging, and medication assistance to patients in need, as determined by social workers.

The OSHU Knight Cancer Institute also has a dedicated social worker who specializes in coordinating lodging and transportation to assist patients getting to and from treatments, given the vast geographic area and distance many patients must travel for services. In 2019, OHSU opened the Rood Family Pavilion—a 5-story guest house managed by the Ronald McDonald House with 38 suites for pediatric and 38 suites for adult patients and their families—to support patients undergoing longer treatments.

To address health literacy issues and ensure language is not a barrier for patients, the institute facilitates translation services through Zoom to assist patients. Most patient educational materials are currently available in Spanish and the institute is working on expanding this to include materials in Russian and Vietnamese.

The OSHU Knight Cancer Institute also offers expansive telehealth and virtual care services for its patients as a means of improving access to care. The institute conducts virtual assessments for patients and virtual care giver support groups, including five social workers assigned to provide psychosocial support for hematologic malignancies. Telemedicine is also an option for standard of care patients who qualify, where patients can get lab work done locally where they live and participate in virtual clinic visits through the institute. As Dr Spurgeon describes, “One of our goals is to make sure patients get to stay in their community for care when they can. Because of all these barriers to care, if it’s a standard of care patient, we may do a virtual visit or connect them to an oncologist in a community program closer to them for care.”

Finally, to further support its aging patient population, the institute recently launched a multidisciplinary gerontology program that addresses aging needs such as mobility and assistive devices/equipment to augment their oncology supportive care for patients with chronic lymphocytic leukemia.

## Partnerships and Programs

The OSHU Knight Cancer Institute maintains strong partnerships with community and patient advocacy organizations to promote awareness and offer additional resources, including the Leukemia & Lymphoma Society, the CLL Society, American Cancer Society, the Pancreatic Cancer Action Network (PanCan), Pink Lemonade Project, the Ovarian Cancer Alliance, Familias en Acción, and state and federal resources such as Social Security and Adult and Family Services.

Locally, the OSHU Knight Cancer Institute collaborates through its Community Partnership program. Currently in its eighth year, this program offers small- to medium-sized grants to communities on a mission to reach and serve vulnerable populations facing disparities due to race, ethnicity, financial need, or other factors. The institute has worked closely with cancer advocacy group ACCION in the Hispanic community and has partnered with several African American parishes to conduct screening and outreach through faith-based communities. One grant recipient, one of OSHU Knight Cancer Institute's own physicians, is currently examining lay navigation for the Hispanic population, with an aim to better address this population's access challenges due to lack of transportation and residence in remote, rural areas. Another initiative underway includes an association between OHSU's Relational Leadership Institute and a local community clinic in southeast Portland focused on health equity and leadership. "It's something that's quite incipient, but it's quite powerful. These cohorts work with the Latinx community on how they can find their voice in advocacy, mostly in healthcare, but also in workplace discrimination against Spanish speakers and other less equitable situations they may face. So, it is patients and community members working together in action that transcends healthcare," explains Laila Craveiro, DNP, MLA, BA, RN, OCN, and senior director of ambulatory oncology.

## OHSU's Approach to Clinical Care Services

Building upon its strong partnerships in local communities, advocacy organizations, as well as with local hospitals, the OSHU Knight Cancer Institute extends its reach to support patients from underserved communities through referrals, clinical trials, access to affordable medications, and more.

The institute has developed a patient-centralized referral

program and actively works with external providers to screen referrals. Each captured referral generates a "We Got It" response within the first day of receipt to notify the referring provider the referral was received and to promote better care coordination.

The institute is actively involved in clinical trials and regularly assesses patient eligibility and provides patient education to encourage enrollment. Connecting patients to clinical trials are done through multiple channels, including the Leukemia & Lymphoma Society, the CLL Society, as well as other direct outreach to other community practices, which is why partnership-building has been a top priority for the institute. The Rood Family Pavilion has also been instrumental in enabling patients from underserved areas to come to the institute and participate in these complex clinical trials. As Dr Spurgeon explains, "Patients can always be treated in the community with standard of care where they live, and that's our goal. But it is our duty to put every [eligible] patient if we can on a clinical trial. It is our job to have [access to] lots of good clinical trials."

In addition, the OSHU Knight Cancer Institute maintains its own specialty pharmacy for patients managed by a team of dedicated pharmacists who track medication adherence and provide direct patient education on side effects. The Pharmacy Department offers a medication assistance program to support patients and works closely with clinical care coordinators to identify free drugs through pharmaceutical companies, collaborate with pharmacy benefit managers (PBMs), and provide other needs-based solutions to patients.

## Future Direction

As the OSHU Knight Cancer Institute forges ahead, it has plans to continue to build strategic alliances with local communities, hospitals, and advocacy organizations. The institute shall continue to advance its patient and clinical support services to address regional barriers and provide patients with chronic lymphocytic leukemia greater access to quality health care and oncology services closer to home.

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The **Association of Community Cancer Centers (ACCC)** is the leading education and advocacy organization for the cancer care community. For more information, visit [accc-cancer.org](https://www.accc-cancer.org)

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