

# Advancing Regional Care for Patients With Chronic Lymphocytic Leukemia

## Spotlight on Pontchartrain Cancer Center

Chronic lymphocytic leukemia, the most common form of leukemia in adults accounting for one quarter of new leukemia cases annually,<sup>1</sup> is a comparatively rare hematologic cancer. Frequently diagnosed in community care settings during treatment for other, unrelated conditions, patients may face significant regional disparities and often have limited access to specialty 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 Pontchartrain Cancer Center's unique position as a small-sized community care practice with a personalized approach to caring for patients with chronic lymphocytic leukemia.

### Pontchartrain Cancer Center

**Location:** Covington, Louisiana and  
Hammond, Louisiana

**Center Type:** Community Oncology Program



### Pontchartrain Cancer Center

Pontchartrain Cancer Center is an independently owned community oncology and hematology practice in Louisiana. With 2 offices in Covington and Hammond, strategically located to serve the rural corner of Louisiana close to the Mississippi state line as well as southeast Louisiana near downtown New Orleans, Pontchartrain Cancer Center offers high-level expertise, multispecialty infusion, and phase Ib- to IV clinical trials in a local, community care setting. Founded in 2005 and led by board-certified hematologist and medical oncologist David Oubre, MD; and CEO Kathy Oubre, MS, the center is supported by a team of 3 oncology-certified nurse practitioners, 3 clinical research staff, 4 full time and one part-time infusion-registered nurses, 2 financial counselors, and other support staff who provide comprehensive oncology care in a

variety of hematologic disease conditions, including chronic lymphocytic leukemia. The center also features a medically integrated dispensing pharmacy and a hot lab for administration of radiopharmaceuticals.

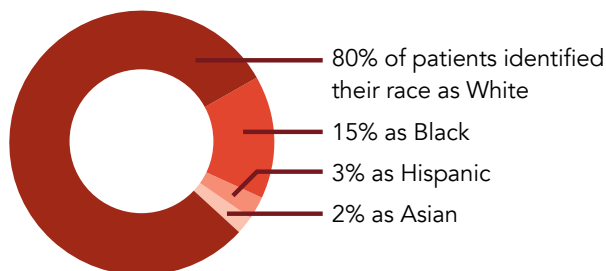
Despite its size, Pontchartrain Cancer Clinic's impact is far reaching through its strategic alliances and involvement with the Society for Clinical Research Sites, Quality Cancer Care Alliance, Community Oncology Alliance, and National Community Oncology Dispensing Association. Dr Oubre serves as the Louisiana representative for the State Affiliate Council for the American Society of Clinical Oncology and is the former president of the Louisiana Oncology Society.

## Patient Profile

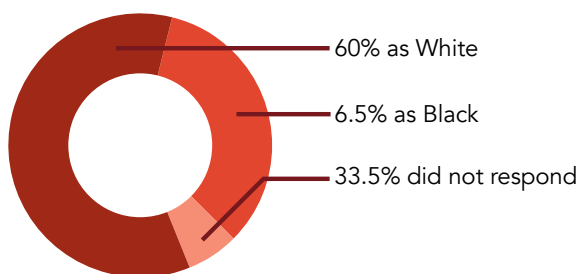
Pontchartrain Cancer Center sees approximately **800 new patients per year** and of these:

- **47** have received a diagnosis of chronic lymphocytic leukemia
- **14** of these patients are in active treatment
- **29** are under monitoring with no active treatment
- **4** patients are in remission.

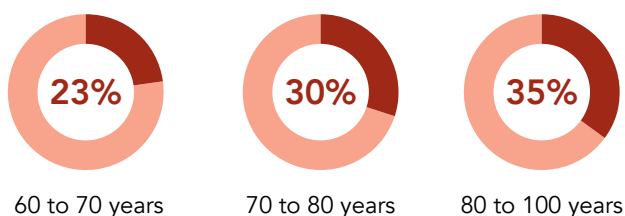
Pontchartrain Cancer Center serves a large, primarily rural patient population. According to its most recent patient demographics report, approximately:



Of those diagnosed with chronic lymphocytic leukemia, patients identified their race as:



Most patients seen at Pontchartrain Cancer Center are aged 60 years or older, which includes patients with chronic lymphocytic leukemia



Nearly all patients speak English as a primary language, although several patients only speak Spanish and 2 patients are deaf.

In terms of payer mix, most patients are covered through:

**55%** a fee-for-service (FFS) Medicare plan

**20%** Medicare Advantage | **25%** commercial insurance plan

with a nominal group covered through Medicaid.

## Addressing Regional Challenges

According to the Centers for Disease Control and Prevention, Louisiana has one of the highest cancer mortality rates and the largest disparities in cancer deaths between Black and White individuals.<sup>3</sup> Further, the National Cancer Institute (NCI) reports that residents living in rural areas experience significant health equities 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 Louisiana, 13.5% of people are uninsured, 14% of families are living below poverty, and 28.9% are living below 150% of poverty (higher than the national average of 8.9% and 20.7%, respectively), according to NCI state cancer profiles.<sup>5</sup>

Regionally, the most common barriers to care for patients seen at the Pontchartrain Cancer Center include food insecurity, transportation, and health literacy, all key social determinants of health. With no public transportation available in the service area, patients must drive themselves or rely on caregivers and friends for rides, sometimes traveling more than 30 miles for a clinic visit. Because patients with chronic lymphocytic leukemia are generally aged 60 years or older, and most of the center's patient population is older than 70 years, transportation is a significant barrier to care. Health literacy also presents another major challenge, as the center struggles with limited levels of literacy in its patients.

Although Pontchartrain Cancer Center operates as a private practice, its infusion nurses and care staff often act as nurse navigators and work diligently to ensure that patients are screened for social determinants of health to identify patient-specific barriers. Upon diagnosis and establishment of any treatment plan with out-of-pocket expenses estimated to exceed \$100, the care team will assess patients and screen for household size, income level, level of family support, and access to transportation to determine barriers and identify support options. Financial hardships pose a heavy burden for the center's patients given the variable payment structures between oral and infusion oncologic agents, reported challenges with Louisiana Medicaid coverage, and challenges securing insurance coverage for patients who are Mississippi residents and cross state lines for care. Therefore, Pontchartrain Cancer Center seeks financial assistance and drug assistance programs for nearly all patients.

To help address health literacy barriers, all patient education is targeted at an eighth-grade literacy level. Pontchartrain Cancer Center schedules comprehensive, 1-hour patient education visits with a nurse practitioner for all patients with a new cancer diagnosis to address questions, identify needs, and discuss care guidelines and adverse effects of medications. The center's staff prepare personalized binders for each patient—inclusive of information about the clinic, the patient's disease, relevant resources, availability of clinical trials, FAQs, a glossary of commonly used terms, an outline of the treatment plan, a monthly calendar notating upcoming lab visits, radiation appointments, infusion appointments, and a treatment regimen schedule (ie, which drugs are to be taken on which days)—and during visits, care staff will summarize important notes and facts in simple bullet points for patients. For patients with chronic lymphocytic leukemia, these binders are particularly helpful, as patients often have a complicated regimen. The center encourages these patients to bring a caregiver or advocate, usually a friend or family member, with them to appointments to help discuss care plan management, but at minimum, ensures that the patient's binder goes home with patients to caregivers at home.

In addition, for patients with chronic lymphocytic leukemia who rely heavily on oral-based regimens (eg, Bruton tyrosine kinase inhibitors), the care team prepares color-coded medication pill boxes for identified patients who struggle with

medication adherence. Karen Stephens, RN; and Courtney Tregre, RN, director of research explain: "For some patients with limited literacy, we will get them a pillbox from a drug representative, and we will stock their pillbox for them while they are here at the visit. We tried a calendar [to support medication adherence] and [patients did not understand] that; so, we went back and color-coded the pillbox for them so they understood. We color-code their [medication] bottles and we color-code the bottle to match the calendar. Whatever it takes to help the patient...it's the beauty of private practice."

As a small, private practice, access to specialists such as dietitians or social workers is limited, and staff must rely on local community resources to provide nutritional support for patients. For patients who struggle with English and for the center's deaf patients, care staff hire and arrange for translators to be present during clinic visits.

Beyond this, Pontchartrain Cancer Center has working relationships with several home care providers in the service area to obtain approval for skilled home care visits for blood pressure management and targeted patient monitoring for their older and frailer patients. The center seeks patient starter kits for blood pressure home monitoring and ensures patients are checked regularly at every clinic visit as well as at primary care physician visits. The center also has defined survivorship appointments and coordinates closely with a patient's primary care provider providing supporting clinical documentation to ensure needs are met.

As Dr Oubre explains, "We don't have access necessarily to some of the things that might be available in larger centers, but we do have access to the patient. So, we know them pretty well. And we know what's available in the community."

## Partnerships and Programs

This knowledge of community resources, gained through strong partnerships with local and state advocacy organizations such as the Council on Aging, the American Cancer Society's Baton Rouge branch, the local health department, and local churches and charitable organizations, has helped Pontchartrain Cancer Center work creatively to provide an extensive array of resources to support the needs of their patients.

Through these partnerships, the care team has been successful in sourcing and obtaining nutritional support for patients, Visa cards for gas, hotel vouchers, financial assistance, and funding for childcare as needed. Collaboration with local nonprofit organizations such as Council on Aging St Tammany Parish, enables patients use the STAR transit system, which provides rural and urban transportation for patients as well as free transportation for riders aged 60 years and older.

Pontchartrain Cancer Center also conducts patient outreach and education through Facebook, the center's website, and patient forums. Through its involvement with organizations like the Cancer Oncology Alliance Patient Advocacy Network (CPAN) and SPARK, an identity and self-esteem building program for women impacted by a cancer diagnosis, the center connects patients with regional and national organizations for support. Pontchartrain Cancer Center also works with community hospice providers to seek support as well as provide palliative care and end-of-life support groups.

In terms of chronic lymphocytic leukemia awareness and cancer care management, Pontchartrain Cancer Center is very active at the local level. All staff nurses are involved in the Oncology Nursing Society (ONS) and attend monthly meetings, and the clinical team and chief executive officer attend quarterly educational meetings with pharmaceutical representatives and regular ONS meetings.

### **Pontchartrain Cancer Center's Approach to Clinical Care Services**

Given its rural health care setting, Pontchartrain Cancer Center serves as the primary care center for about half of its patients, providing integrated principal care management along with oncology care support. The center prides itself on being patient focused and seeks to be responsive to all their care needs, including other comorbidities, such as diabetes. As Tregre describes, "Patients see us as their medical home for all their needs," and are accustomed to contacting the center for both oncology and non-oncology concerns.

Utilizing National Comprehensive Cancer Network (NCCN) guidelines for oncology management and an oral chemotherapy adherence program for patients with chronic lymphocytic leukemia, Pontchartrain Cancer Center's clinical care is comprehensive. Although the center does not

conduct enrollment in the national cancer registries, it links patients to a registry if interested. Staff report their patient population has expressed concerns about sharing their personal information and are wary of public databases.

Pontchartrain Cancer Center maintains its own medically integrated dispensary and monitors pharmacy costs, fills medications internally, and utilizes a patient care plan to track medication adherence and timeliness to care. The center reports that medications are filled in less than 1 week on average, and Pontchartrain offers a robust oral adherence program.

Pontchartrain Cancer Center has been participating in clinical trials since 2016 and offers phase Ib to IV clinical trials at both its Covington and Hammond locations. Using the clinical support tool OncoTrials to identify patients, the center's clinical research team works closely with patients to educate and determine good clinical trial options. The center posts a comprehensive list of all available trials on its website and conducts weekly research meetings to assess patient eligibility and provide patient outreach education. The care team also works extensively to source financial resources to support patients' relocation during clinical trials, including hotels, lodging, meals, childcare, and other support for patients who may travel over 100 miles for participation. The center has had high participation in clinical trials across all demographics despite accessibility hurdles and challenges in identifying qualifying parameters, and the clinical care team attributes this success to their uniquely individualized patient care and ability to establish close patient relationships.

### **Future Direction**

Pontchartrain Cancer Center continues to see new patients every week for medical oncology care, hematologic malignancies, and benign blood disorders. With new phase Ib to IV clinical trials becoming available and advancements in treatments, Pontchartrain Cancer Center anticipates extending its reach regionally and working with more community organizations for support to help improve outcomes for the patients in its care. The center is uniquely positioned to provide world-class treatment for its patients close to home and is on a mission to continuously improve its workflows, operations, and offerings to best serve its patients.

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