

# Understanding Racial Differences and Disparities in PBC Care

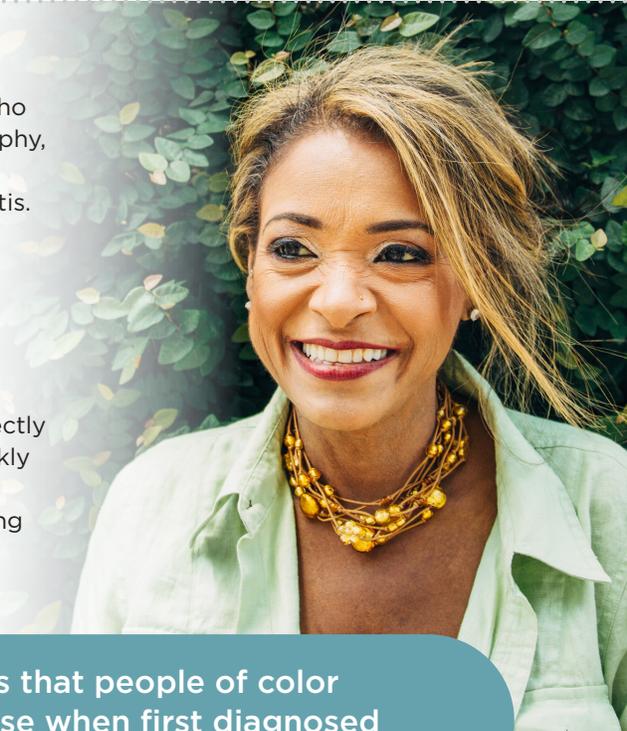
There have been important advances in primary biliary cholangitis (PBC) research, treatment, and education in recent years, but many opportunities remain to improve patient care. The impact of racial differences and disparities in PBC remains poorly understood, and the full diversity of the PBC patient community is not always represented in educational materials for healthcare providers and patients.

## MEET BEL

Bel is a liver transplant survivor and a mom living with PBC. In 2009, Bel, who works as a St. Cloud State University professor in the Department of geography, had been experiencing unusual itching and fatigue. She saw a liver specialist for these symptoms and was initially misdiagnosed with autoimmune hepatitis.

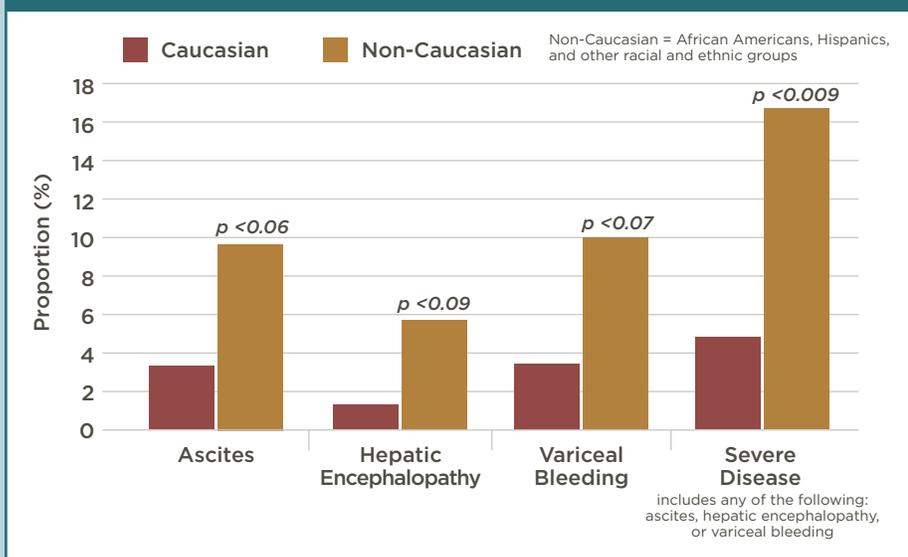
*“When healthcare providers think about what a person with PBC looks like, the image in their head doesn’t look like me.”*

She tried 27 different medications for intractable pruritus before being correctly diagnosed with PBC three years later in 2012. Bel advanced to cirrhosis quickly following her late diagnosis and suffered countless hurdles and hardships as she navigated the liver transplant process. In 2018, she received her life-saving liver transplant, but her recovery remains difficult. Bel believes that her race contributed to her late diagnosis and sub-optimal care.



Bel’s story is one of many. Research suggests that people of color living with PBC tend to have more severe disease when first diagnosed and experience worse outcomes in the long run.<sup>1,2,3,4</sup>

## PBC Disease Severity at Presentation<sup>1</sup>



## WHAT DOES THE RESEARCH SHOW?

Among large multi-center U.S. study of 535 patients with PBC, significant disparities in severity of disease at presentation were observed:

- Compared to Caucasians, African American and Hispanic PBC patients at presentation had 3 times greater prevalence of ascites, 5 times greater hepatic encephalopathy, and 3 times greater history of variceal bleeding.<sup>1</sup>

Additionally, compared to non-Hispanic whites, several studies have found that ethnic minorities with PBC have significantly higher mortality.<sup>2,3,4</sup>

## PATIENT PERSPECTIVES ON RACIAL DISPARITIES IN PBC CARE

Patient perspectives on racial disparities in PBC care have not been adequately studied and are currently not reflected in medical literature. Recently, the Global Liver Institute (GLI) asked a small sample of patients of color with PBC to share insights about their journey with the disease, and several key themes emerged<sup>5</sup>:



Reducing PBC care inequities in people of color begins with improving the patient-provider relationship in shared decision making and recognizing the signs and symptoms early enough so the journey to diagnosis and treatment can begin.

### Reminders for PBC Diagnosis

- PBC is more common in women over 40, but younger patients can have PBC as well<sup>6</sup>
- PBC is more common in patients with other autoimmune diseases<sup>7,8</sup>
- Pruritus (itching) and fatigue are the most common symptoms, but not all patients are symptomatic<sup>8</sup>
- Look for elevated Alkaline Phosphatase (ALP) lab tests<sup>8</sup>
- An Antimitochondrial Antibody (AMA) lab test can confirm diagnosis for most patients<sup>8</sup>

<sup>1</sup> Peters, et al. *Hepatology*. 2007 ;46(3):769-75.

<sup>2</sup> Cholankeril, et al. *Clin Gastroenterol Hepatol*. 2018 ;16(6):965-973.

<sup>3</sup> Galoosian, et al. *Dig Dis Sci*. 2020;65(2):406-415.

<sup>4</sup> Sayiner, et al. *Hepatology*. 2019;69(1):237-244.

<sup>5</sup> Global Liver Institute. 2021

<sup>6</sup> Hirschfield. *Best Pract Res Clin Gastroenterol*. 2011;25(6):701-712.

<sup>7</sup> Carey, et al. *Lancet*. 2015; 386(10003):1565-75.

<sup>8</sup> Lindor, et al. *Hepatology*. 2019;69(1):394-419.