COMMUNITY LIVER ALLIANCE ™
GLOBAL AWARENESS. LOCAL IMPACT.

Annual PBC Update

OCTOBER 16, 2024
6:00 P.M. - 8:00 P.M. ET

Impact Report

Overview

The Community Liver Alliance (CLA) hosted its annual Primary Biliary Cholangitis (PBC) Update to provide patients and caregivers with current, relevant information to help manage their condition and advocate for optimal care. The program reinforced CLA's commitment to education, empowerment, and community connection for individuals impacted by autoimmune liver diseases.

Primary Biliary Cholangitis (PBC) is a chronic, progressive autoimmune liver disease characterized by the immune-mediated destruction of the small intrahepatic bile ducts, leading to cholestasis, fibrosis, and potentially cirrhosis if untreated. Though once considered rare, increased awareness and improved diagnostic tools have contributed to higher recognition and diagnosis rates in recent years.

Prevalence and Incidence

- PBC predominantly affects women, with approximately 90% of cases occurring in females, typically between the ages of 40 and 60 years old .
- In the United States, the prevalence of PBC is estimated to be between 39 to 402 cases per 1 million persons, with incidence rates ranging from 0.9 to 5.8 cases per 100,000 person-years, depending on the region and study methodology .
- A 2023 study estimated that up to 130,000 individuals in the U.S. may be living with PBC, many of whom are undiagnosed or misdiagnosed .

Disease Progression

- PBC is a heterogeneous disease. While many patients remain asymptomatic at diagnosis, up to 50% may develop symptoms such as fatigue, pruritus (itching), and right upper quadrant pain within a few years .
- Without treatment, PBC can progress to cirrhosis, portal hypertension, liver failure, and the need for liver transplantation. Liver transplantation is required in approximately 5–10% of patients with advanced disease .

Treatment and Outlook

- The first-line treatment for PBC is ursodeoxycholic acid (UDCA), which improves transplant-free survival in patients with early-stage disease .
- For patients who do not respond adequately to UDCA, obeticholic acid (OCA) was approved as a second-line therapy in 2016. More recently, fibrates (e.g., bezafibrate, fenofibrate) have shown promise in clinical trials and are increasingly used off-label in the U.S..
- Early diagnosis and initiation of therapy are strongly associated with improved prognosis and quality of life.

Unmet Needs and Disparities

- There are significant delays in diagnosis due to the nonspecific nature of symptoms and lack of awareness among general practitioners.
- Racial and ethnic disparities in diagnosis, treatment access, and outcomes have not been fully studied, representing a critical area for future research and advocacy.
- Patients report persistent unmet needs in areas of symptom control (especially fatigue and itching), emotional support, and nutrition guidance.

References

1. Lindor, K.D., Bowlus, C.L., Boyer, J., et al. (2019). Primary biliary cholangitis: AASLD practice guidance 2018 update. Hepatology, 70(1), 142–165. doi:10.1002/hep.30536
2. Kaplan, M.M., & Gershwin, M.E. (2005). Primary biliary cirrhosis. New England Journal of Medicine, 353, 1261–1273.
3. Foundation for Rare Liver Diseases. (2023). PBC Awareness Campaign Report.
4. Selmi, C., Mayo, M.J. (2010). PBC and Fatigue: Clinical Perspectives. Clinical Liver Disease, 14(3), 423–435.
5. European Association for the Study of the Liver (EASL). (2017). Clinical Practice Guidelines: The diagnosis and management of PBC. Journal of Hepatology, 67(1), 145–172.
6. Lammers, W.J. et al. (2014). Survival of PBC patients: Impact of response to therapy. Gastroenterology, 147(6), 1338–1349.e5.
7. Hirschfield, G.M., et al. (2021). Fibrates in PBC: Mechanism and outcomes. Journal of Hepatology, 75(5), 1093–1105.

Program Goals

1. Help patients to understand and know more about their medical conditions and health situation.

2. Educate patients and caregivers with the most relevant, current, consistent and updated information.

3. Aim to provide information to assist patients and their families in the medical care and decision-making process.

4. Solicit feedback on program content and other areas of interest for future programming considerations.

Program Agenda



Alex Myint, MD
Clinical Assistant Professor of Medicine
Transplant Hepatologist
VA Pittsburgh Healthcare System

Dr. Myint graduated from Texas A&M University System Health Science Center College of Medicine in 2010.

Program Highlights

Dr. Alex Myint delivered a comprehensive and engaging presentation that covered key clinical and lifestyle topics associated with PBC, fostering a better understanding of disease management and treatment options. The virtual format ensured accessibility for participants across geographic regions.

Topics Covered

- Understanding Lab Tests: How to interpret common liver function tests and biomarkers specific to PBC.
- Communication with Providers: Essential questions to ask hepatologists and how to coordinate care with primary care providers.
- Therapeutic Advancements: Updates on new and emerging treatments in the drug development pipeline for PBC.
- Medication Considerations: Guidance on managing medication interactions, including supplements and over-the-counter drugs.
- Symptom Management: Strategies to manage fatigue, itching, and other common symptoms associated with PBC.
- Nutrition and Diet: Practical advice on how diet may influence disease progression and symptom control.
- Liver Transplantation: When it becomes a consideration and what the evaluation process involves.
- Interactive Q&A: Participants had the opportunity to submit questions in advance and during the session to address personal concerns and experiences.

Program Recording

Engagement and Feedback

Feedback from participants highlighted the program's relevance, clarity, and impact on their disease management journey. Comments included:

- "It was so helpful to hear directly from a hepatologist and learn how to interpret my lab results."
- "I feel more confident asking my doctor the right questions now."
- "Dr. Myint's explanation of treatment options gave me hope for what's on the horizon."
- "Hearing about the transplant process in a non-threatening, informative way was very reassuring."
- "I appreciated that nutrition was discussed. It's not always covered in doctor visits."
- "The format was accessible and comfortable for asking questions—it felt like a true support space."

Over 90% of respondents rated the program as "excellent" or "very good," and many expressed interest in ongoing virtual sessions and a desire for more peer-to-peer interaction opportunities.

To support continuous improvement and future programming, participants were encouraged to complete a post-event survey. The survey aimed to gather feedback on the content, speaker effectiveness, and additional educational needs of the PBC community.

Impact and Takeaways

The 2024 PBC Update successfully connected patients and caregivers with expert clinical knowledge, actionable insights, and a sense of community. The program emphasized the importance of patient-centered care, open communication with providers, and staying informed about therapeutic advancements.

PBC PATIENT SURVEY

Thank you for your ongoing support of our mission

Acknowledgements

Thank you to our expert provider presenter, Dr. Alex Myint.

Thank you to the planning committee for bringing this important program to the liver community.

Thank you to our audience for attending and participating in the breakout session solution dialogue.

Thank you to our generous supporters.

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