

## PSC Partners Comment on the Newly Published AASLD Guidance for Primary Sclerosing Cholangitis (PSC) and Cholangiocarcinoma: Recommendation about the use of Oral Vancomycin in PSC

The American Association for the Study of Liver Diseases (AASLD) <u>released new guidance</u> on the diagnosis and management of primary sclerosing cholangitis (PSC) and cholangiocarcinoma on September 10, 2022 in the journal *Hepatology*. The <u>development of this guidance</u> was an evidence-driven process designed to inform the medical community of the most up-to-date recommendations in clinical care in order to improve PSC and cholangiocarcinoma patient outcomes. This has been a significant undertaking for the AASLD writing group.

In this <u>newly published guidance</u>, the first since <u>2010</u>, the AASLD statement on the use of oral vancomycin reads, "Currently, there is insufficient evidence to recommend the use of oral vancomycin for the treatment of PSC."

[https://aasldpubs.onlinelibrary.wiley.com/doi/abs/10.1002/hep.32771?campaign=wolacceptedarticle]

Prior to the publication of this recommendation, a group of PSC community members expressed distress about an anticipated, yet unpublished statement on the use of oral vancomycin in the guidance for PSC. Based on PSC Partners' long standing relationship with AASLD, PSC Partners leadership actively remained in communication with AASLD to discuss patient needs and perspectives on the use of oral vancomycin.

PSC Partners was founded by a patient, run for years by volunteer patients and caregivers, and continues to be governed by a board of directors, each of whom has a direct connection to PSC. Since our launch in 2005, we have found that the needs of our community are many and varied, and this requires us to maintain robust initiatives and strong, lasting relationships.

PSC Partners has worked internationally with the medical, regulatory, and industry stakeholders to bring the voice of the patient to the forefront. We believe that the best path forward for the PSC community is for the research community to pursue rigorous placebo-controlled clinical trials in order to determine the safety and efficacy of all therapeutic interventions. We encourage PSC Patients to join the <a href="PSC Partners Registry">PSC Partners Registry</a> and explore participation in surveys, studies, and clinical trials.

<u>PSC Partners does not take a position</u> on the use of any specific off-label medication and instead encourages patients to work with their doctor to discuss a treatment plan. As part of our mission, we provide education and support groups in order to empower PSC patients to make informed decisions with their physician.

PSC Partners is very grateful to the many clinicians and researchers who provide expertise and support, evidence-based clinical care, and career dedication to the pursuit of treatments and a cure for PSC.