

**PSC Partners Seeking a Cure and PSC Support Announce a Call to Action for Medical Stakeholders to Better Understand and Diagnose Rare Liver Diseases**

*Nonprofit patient group to educate on Rare Liver Disease Diagnosis at The Liver Meeting 2016*

Greenwood Village, CO -- Nov. 10, 2016 -- PSC Partners Seeking a Cure, a nonprofit organization that provides education, support, and research funding for the rare liver disease primary sclerosing cholangitis (PSC), and PSC Support, the UK-based nonprofit organization, have announced a call to action for medical stakeholders to be cognizant of the value to patients of better understanding and diagnosis of rare liver diseases. PSC Partners Seeking a Cure will be spearheading this patient-led initiative, with the support of medical health professionals treating liver diseases, at The Liver Meeting, the annual conference of the American Association for the Study of Liver Diseases (AASLD), in Boston, Nov. 11-15, 2016.

The Liver Meeting, which attracts more than 9,500 hepatologists and other health professionals to exchange the latest research and news on liver diseases, will give PSC Partners Seeking a Cure a platform to address a critical issue in the field of hepatology: the consequences of misdiagnosing rare diseases and thereby providing inadequate treatments and disease management for patients, leading to missed opportunities for participation in groundbreaking clinical trials. With the recent renaming of another liver disease, primary biliary cholangitis (PBC), formerly called primary biliary cirrhosis, an opportunity has arisen to educate clinicians and stress the importance of avoiding confusion identifying these two distinctly different bile duct diseases, PBC and PSC.

“We are seeing confusion in identifying the two diseases in medical publications, among regulatory bodies, and in medical practice. The two conditions are confused all too frequently. We are strongly committed to raising awareness of the situation among medical stakeholders, and making sure that everyone with rare liver disease gets a prompt and accurate diagnosis,” said Ricky Safer, CEO and founder of PSC Partners Seeking a Cure. “The rarity of the two diseases and the similarity in the names of the two diseases risk perpetuating a misconception among those without expertise that the two conditions are the same. It can be damaging for patients to subsequently receive poor medical advice about their futures because of inadequate diagnosis, or misunderstanding of their disease by treating clinicians”.

Primary biliary cholangitis (PBC), made headlines last year after it underwent a name change from primary biliary cirrhosis to primary biliary cholangitis. The name change initiative, led by patients, removed “cirrhosis” from the disease name to prevent the misconception that PBC is caused by alcohol overuse and to avoid the stigma attached to the word “cirrhosis”. As a result of new treatments and better diagnosis, cirrhosis no longer characterizes the disease as often.

The term cholangitis has various interpretations, and non-experts with little exposure to either of these rare liver diseases, might mistakenly think that the cholangitis of PBC, is interchangeable with the inflammatory, scarring and infective cholangitis of PSC. While both diseases involve the inflammation of bile ducts connected to the liver, PSC, unlike PBC, has no effective medical treatments and has the additional factor of overlapping inflammatory bowel disease (ulcerative colitis or Crohn’s Disease) in 80% of its population, a burden that often falls to young patients in their 30s and 40s.

PSC is now the leading indication for transplant among the family of rare autoimmune liver diseases and while it is the least common, these patients live with an expectation that a majority will need liver transplantation to prolong life.

Patients with PSC also have a devastating and distinctly increased risk of colon and bile duct cancers, while patients with PBC fortunately do not have increased risk for either of these cancers. Consequently, patients with PSC need special cancer surveillance, as well as advice on how to live with cancer risk in a way that is supportive and not life limiting.

“It is important that the community at large recognize how important we think it is for patients with rare liver diseases to get prompt and accurate diagnoses, and that through broad education we can raise standards for all, and avoid any confusion in the management of these important liver diseases,” said Professor Gideon Hirschfield, Professor and Consultant Hepatologist at the University of Birmingham and University Hospitals Birmingham, UK. “Patients with PBC may have unfounded concern raised about infection and malignancy risk. Moreover, patients with PSC, a disease with such a great unmet therapeutic need, may face further confusion in timely diagnosis by non-specialist clinicians. At a time of great interest and excitement about new treatments for patients with biliary diseases, it is now more than ever opportune to focus on education to improve the care of our patients, and make sure that in the study of both diseases we truly understand their causes and rapidly develop better treatments for all.”

International clinical trials are currently underway. They are fully enrolled by patients with PSC who are eagerly awaiting a medical intervention with proven benefit.

Collectively, it has never been more apparent as to how important accurate understanding of these diseases is. A misdiagnosis would mean a patient not getting effective treatment for PBC, and a patient not undergoing crucial cancer surveillance for PSC.

To learn more about the differences between PSC and PBC, attendees of The Liver Meeting, including hepatologists, gastroenterologists, and internists are encouraged to visit PSC Partners Seeking a Cure at Booth #1 on Foundation Row for educational materials on identifying and diagnosing both diseases, or visit <http://pscpartners.org/psc-and-pbc/>

#### **About PSC Partners Seeking a Cure**

PSC Partners Seeking a Cure is a nonprofit organization that provides education and support for people affected by the rare liver disease primary sclerosing cholangitis (PSC). Formed in 2005, the organization raises funds to research the origins, treatments, and a cure for the disease. Education and research initiatives of PSC Partners Seeking a Cure include annual conferences for PSC patients and their caregivers; a competitive PSC research grant program; an IRB approved patient-driven registry created in collaboration with the NIH; a comprehensive website for patients, caregivers, and medical professionals; local and online support groups; and a PSC literature site, the most extensive online collection of studies on PSC and related diseases. To learn more, visit [www.pscpartners.org](http://www.pscpartners.org).

**About PSC Support**

UK based PSC Support is a nonprofit charity organization whose mission is to improve the lives of people with primary sclerosing cholangitis. PSC Support informs, funds and supports high quality scientific research, provides emotional support and networking to PSC patients and their families in over 150 countries, takes action to improve PSC-related liver disease and organ transplant policies and services, and provides education and awareness about PSC to patient communities and medical professionals. To learn more, visit [www.pscsupport.org.uk](http://www.pscsupport.org.uk).

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