

PBC patients desire more information

A recent survey shows there's a lack of information available about primary biliary cholangitis (PBC), formerly known as primary biliary cirrhosis. PBC is a rare, chronic autoimmune disease that affects the liver. Since 1988, it has been the second-leading overall cause of liver transplant in women in the U.S. People living with **PBC** and the physicians that care for them **need more information to help** facilitate better conversations about living with this disease.

Doctors report PBC medical

information is limited



About the RAPID Survey

The RAPID (Raise Awareness of PBC and Importance of Liver Disease) Survey was commissioned by Intercept Pharmaceuticals, Inc. to help increase public knowledge about liver health and highlight opportunities to improve care in PBC. Three separate quantitative surveys were conducted with the following audiences:

to better understand their disease **66%** think there is not enough information about **PBC** published in medical journals More than 1/3 think that current PBC and presented at medical conferences information available is fair or poor Doctors indicate that it is often Patients struggle to find difficult to identify and diagnose PBC "the right doctor" 93% of physicians surveyed believe PBC is often 86% had to visit more than one missed or misdiagnosed doctor prior to diagnosis **ALP***, a biomarker that can be 90% of Americans do not know tested in the blood, is a key what would be considered ideal prognostic indicator and doctors' liver function test results **#1 metric for monitoring PBC** 64% rely on it a great deal and 57% select it as the metric they rely on most Just 32% of PBC patients ... and doctors overstate the share of know their current ALP score their patients who should know their target ALP score 61% among doctors **vs.** 36% among patients

For more information about PBC, visit: www.livingwithPBC.com

WHAT'S ALP?

*High Alkaline Phosphatase (ALP) is a key measure of disease progression in patients with PBC.

1. Physicians

From December 11, 2014 to January 12, 2015, a total of 322 physicians (262 gastroenterologists and 60 hepatologists) took part in an online survey. To qualify, doctors had to be board-certified, have been practicing for at least two years and have treated at least two PBC patients in the previous six months.

2. Patients

From January 5-30, 2015, 214 patients who had been doctor-diagnosed with PBC took part in an online survey.

3. General Public

From January 6-12, 2015, a sample of 511 Americans took part in an online survey. This study was conducted using GfK KnowledgePanel, which is representative of the American public and covers 97% of U.S. households.

