



Some are asking why we “no” longer use the name Primary Biliary Cirrhosis for PBC.

As most of you know, the name Primary Biliary Cirrhosis (PBC) was very deceiving and carried a stigma with its diagnosis. For years PBC wasn't diagnosed until late disease stage and the patient had developed cirrhosis and in some patients' liver failure. It also carried a stigma of alcohol and drug abuse, although most patients didn't even drink alcohol.

Since 1995, there have been many improvements for the PBC patient by way of early diagnosis and medications, which slow the disease's progression. As treatments improve, most patients diagnosed with PBC will never reach cirrhosis stage, need a liver transplant or be at risk of dying. So, changing the PBC name to accurately describe the disease was necessary.

Changing the name of PBC had been discussed for years among both patients and the medical community, but nothing was ever done. In April 2014, at the London EASL Conference, changing the name of PBC became more than just a quick point of discussion. A panel of patient advocates and medical experts met and discussed the need to change the name, not only for the sake of the patients, but also to help the medical professionals treating PBC patients. The name change discussion continued at the Milan European Association for the Study of the Liver (EASL) Symposium and at the 2014 PBCers Las Vegas PBC Conference.

PBC organizations and support groups joined hands with medical professionals and facilities to change the name of primary biliary cirrhosis to more accurately describe what the diagnosis of “PBC” meant to medical professionals and patients. After much discussion, the name they felt described PBC the best was Primary Biliary Cholangitis. The word cirrhosis would only be used in late stage 4.

The “Name Change Initiative” suddenly took on a life of its own with the help of worldwide medical professionals such as Doctors Ulrich Beuers, Eric Gershwin, Robert G. Gish, Pietro Invernizzi, David Jones, Keith Lindor, Xiong Ma, Ian R. Mackay, James Neuberger, Albert Par_es, Raoul Poupon, Atsushi Tanaka, John M. Vierling and many more. Medical facilities such as Mayo Clinic, University of CA at Davis, Stanford, Baylor and others offered their help.

By May 2015, the name Primary Biliary Cholangitis had been approved by both the AASLD (American Association for the Study of Liver Diseases) and EASL (European Association for the Study of the Liver). The next step was the World Health Organization (WHO) approving the name change to use in the new 2018 worldwide medical codes. PBC Patients, Medical Professional and PBC/Liver Disease Organizations worked tirelessly with WHO to get the name changed by the deadline.

Late 2016, WHO approved the name Primary Biliary Cholangitis and the name change promotion began in early 2017. Today, medical facilities, doctors, pharmacies and insurance companies use the new ICD-11 codes under the name Primary Biliary Cholangitis.

WHY THE NAME CHANGE?

After a long collaborative effort among PBC patient organizations, physicians and researchers around the world, the acronym PBC now has a more accurate official designation: **PRIMARY BILIARY CHOLANGITIS**



To us, a name is more than just a **NAME**.



The former name, "Primary Biliary Cirrhosis," was inaccurate and problematic for a number of reasons:

1

The majority of patients with PBC are now commonly diagnosed in the early stages of the disease.

2

With current available therapies for PBC, the vast majority of these patients will never progress to cirrhosis.

3

Negative connotations associated with the word cirrhosis inappropriately stigmatize patients.

Changing the name from Primary Biliary Cirrhosis to Primary Biliary Cholangitis solved these problems, while retaining the globally recognized abbreviation PBC. In addition, the term Cholangitis, which means inflammation of the bile ducts, captures the true essence of PBC where the immune system attacks and destroys the cells lining the small to medium caliber bile ducts.

<http://pbcers.org>

UPDATE

The Name Change from Primary Biliary Cirrhosis to Primary Biliary Cholangitis was approved by EASL in the fall of 2014 and by AASLD in May 2015.

The final step in the process to change the name from Primary Biliary Cirrhosis to Primary Biliary Cholangitis in the new ICD-11 codes that were released by the World Health Organization (WHO) on June 18, 2018.

PBC will be listed as code DB96.1

In addition, PBC with overlap syndrome is code DB96.10

PSC (Primary Sclerosing Cholangitis) is code DB96.2

The PBCers Organization looks forward to these codes being used by our physicians depicting the correct diagnosis name of our disease.



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