

## Who gets PBC?

Women are affected with PBC 10 times more frequently than men. The disease is usually first diagnosed in people 30 to 60 years old. Many patients have no symptoms of the disease and are diagnosed by finding an abnormality during routine liver blood tests. Itching and fatigue are common symptoms along with jaundice, cholesterol deposits in the skin, fluid accumulation in the ankles and abdomen, and darkening of the skin.

Several other disorders are often associated with PBC; the most common of which are impaired functioning of the tear and salivary glands causing dry eyes or mouth. Arthritis and thyroid problems may also be present. Renal stones and gallstones may develop. In late stages of the disease, bone softening and fragility may lead to fractures.

## What is the Future of PBC?

PBC has presented in patients for more than 100 years which has led doctors to make earlier diagnoses. Many clues to the cause of PBC have been uncovered by careful observation of patients over the last five years, but the basic cause is still unknown. Research is following two paths:

- Basic investigation of the cause and development of the disease
- Drug therapy trials, involving a large number of patients around the world, are exploring the potential use of several medications to lessen the symptoms and control liver damage.

## For More Information

Please visit our web site:

[www.pbcers.org](http://www.pbcers.org)

or email us:

[pbcers@pbcers.org](mailto:pbcers@pbcers.org) or [pbclinie@pbcers.org](mailto:pbclinie@pbcers.org)

Those interested in receiving the quarterly newsletter can send a request to:

**PBCers Organization**

**1430 Garden Road**

**Pearland, TX 77581**

If possible, please send a donation of \$15 to cover costs of production and mailing.



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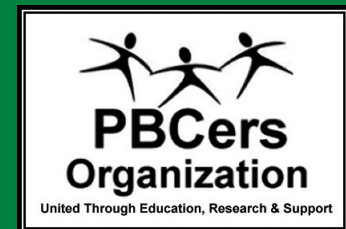


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# The PBCers

*A Support Group  
for Patients with  
Primary Biliary Cirrhosis  
and other  
Cholestatic Liver Diseases*



# The PBCers...

## Who Are We?

The PBCers is an organized support system for people who suffer from Primary Biliary Cirrhosis (PBC) and other cholestatic liver diseases. Patients, family, friends and others who want to learn more about PBC are encouraged to join.

The PBCers exists today because three ladies from different parts of the world, Linie Moore, Joan Dale and Diana Watson, who needed support in dealing with their own PBC, formed an organization in March 1996. Today there are over 2,000 members worldwide in the PBCers Organization.

## What is Our Purpose?

Our purpose is to offer caring support, help, friendship and education to people who suffer from Primary Biliary Cirrhosis, their families, friends, cholestatic liver disease sufferers and anyone else interested in learning more about PBC.

## What are the Goals of the PBCers?

The goals of the PBCers are to offer help and support to all people who suffer from PBC and other cholestatic liver diseases. We do not want anyone to feel alone with PBC.

We strive to help researchers learn the cause and find a cure for PBC, create public awareness of PBC, and raise the level of organ donor awareness.

## How Do We Offer PBCers' Members Help and Support?

The PBCers offer help and support through various

methods including the following:

- The PBCers web site which contains biographies and pictures, a doctor-referral database, and conference information
- The PBCers e-mail, *Daily Digest*, and chat rooms
- Regional group meetings for face-to-face sharing
- "Doctors' Panel Answers the PBCers" – our panel of liver specialists take time to answer our members' questions
- Quarterly newsletter mailed to subscribers
- Annual conferences to share information about our experiences and successes (first conference held January 1999).

## What is the PBC Daily Digest?

The *PBC Daily Digest* is a large e-mail that includes members' e-mails for that day, and since the last *Daily Digest* was published. You must be a subscriber of the PBCers to post messages to the *PBC Daily Digest*.

## How Do I Subscribe to the PBC Daily Digest?

To subscribe to the *PBC Daily Digest* or post a message, send a BLANK e-mail to:

[pbc\\_digest-subscribe@yahoogroups.com](mailto:pbc_digest-subscribe@yahoogroups.com)

## Through Our Efforts...

We have actually made a difference in the fight against PBC and have grown into the largest worldwide support group of its kind. We have achieved more public awareness for PBC and organ donation through the informative home pages for members,

as well as doctors and other medical professionals, for reference in treating and learning more about PBC. Also, we have created a doctor-referral database to help PBCers find leaders in PBC treatment in local communities.

Our various fundraising events, such as the American Liver Foundation's 'Fund for the Cure,' has initiated much needed support for PBC research. Our group has also created three PBCers' quilts for displaying at meetings and conventions (each is filled with love and is a work of art).

## What is PBC?

Primary Biliary Cirrhosis is a chronic liver disease that causes slow, progressive destruction of bile ducts in the liver, thereby interfering with the excretion of bile. In the early stages of PBC, the main problem is the build-up of substances (like bile acids and cholesterol) in the blood, which are normally excreted into the bile. The build-up of substances causes inflammation which leads to destruction of the bile ducts. Continued liver inflammation causes scarring and eventually leads to cirrhosis, which is present only in the later stages of the disease. The diagnosis of PBC is most often made when the patient is still asymptomatic, with abnormal liver biochemistry, as well as the expression of antimitochondrial antibodies (AMA).

## What Can I Do to Help?

Spreading the word about PBC helps everybody affected by the disease. Also, spreading the word about PBC makes everybody aware of ways they can aid in research such as donating to the PBCers Organization or to local and national chapters of the American Liver Foundation (ALF):

ALF 'Fund for the Cure'  
75 Maiden Lane, Suite 603  
New York, NY 10038  
1-800-GO-LIVER  
1-800-465-4837