

What is PBC?

Primary Biliary Cholangitis is a progressive autoimmune liver disease, not related to alcohol or drug abuse.

90% of sufferers are women.

According to a recent study, as many as 1:1000 women over the age of forty may have PBC.

Diagnosis can be difficult and many sufferers are not well-informed about their condition.

There is currently **no known cause or cure for PBC.**

Symptoms

Common Symptoms:

- itching ("pruritus")
 - lethargy and chronic fatigue
- ### Possible related symptoms:
- dry eyes and/or dry mouth (sicca syndrome)
 - joint pains
 - diarrhoea
 - over or under-active thyroid

Possible developments:

- pale stools and dark urine
- bruising
- fluid accumulation in the abdomen (ascites)

Other conditions more common with PBC:

- indigestion
- pain in the abdomen

Advanced liver disease complications include:

- jaundice
- easy bruising
- reddened palms
- swelling of ankles
- swelling of abdomen

The **PBC Foundation** provides help, support and information to sufferers of PBC, their families and friends.

Services include:

A nationwide helpline

Information packs for newly diagnosed patients

Compendium - "Living with PBC"

Self-management workshops

A quarterly magazine for members and the medical professions, offering advice on quality of life issues

Information leaflets for Healthcare Practitioners

Website

National Volunteer Network

Facilitating research projects

Local members' meetings

Raising awareness amongst the general public and throughout the medical professions

The **PBC Foundation** has members in over 65 countries around the world.



foundation

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The **PBC Foundation**

is a nationwide charity providing **help, support and information** to sufferers of PBC and those close to them.

Since its discovery in 1851, names for what we now know as PBC have included "Primary Biliary Cirrhosis", "Xanthomatous Biliary Cirrhosis" and even "Chronic Destructive non-Suppurative Cholangitis". As early as 1959, it was known that Primary Biliary Cirrhosis was **not a medically accurate reflection** of the disease. In order to address this, in June 2015, it was agreed internationally that PBC will henceforth be known as **Primary Biliary Cholangitis**.

Primary Biliary Cholangitis (PBC) is a **liver disease**, not related to alcohol or drug abuse, that mostly affects women. There is no known cure and PBC is one of the main reasons for liver **transplantation** in the UK.



The determination that others should not suffer the ignorance and lack of support

that she suffered when first diagnosed at 38 led Collette Thain MBE, with the support of others, to establish the PBC Foundation.

The PBC Foundation is a nationwide charity run by a small core staff, aided by an international network of Volunteers and is governed by a board of directors. The Foundation is backed by the finest hepatologists in the UK.

Aims and Objectives:

To reach every PBC patient in the UK

To educate the general public and Healthcare Practitioners on all aspects of PBC

To improve the quality of life for PBC sufferers

To find a cause and a cure for PBC

PBC Patients face many difficulties:

The PBC Foundation constantly campaigns to increase awareness of PBC on all levels in order to increase public understanding of liver disease.

There are many negative misconceptions that affect the number of people willing to donate their liver, and thus, potential liver transplantation numbers.

Statutory agencies also need a better understanding and knowledge of the causes and effects of liver disease in order to improve the quality of life for PBC sufferers.

Many PBC patients cannot work and have difficulty obtaining Social Security benefits.

How you can help:

In order to provide our vital services, we rely on donations and fundraising efforts. Here are just some of the ways in which you can help.

1. Donate to us

- Donate regularly by standing order
- Visit www.pbcfoundation.org.uk and donate online
- Donate from your phone by texting PBCF01 £10 to 70070
- Send us a cheque
- Remember us in your will

Did you know? If you are a UK tax payer, and you Gift Aid your donation, you can increase the donated amount by 25p for every £1

2. Fundraise for us

- Get your friends, family and community involved by holding a fundraising event such as a quiz, race night or a coffee morning
- Walk a mile, ride a bike or run a marathon, or get someone to do it on your behalf
- Sell handcrafted goods, hold a charity auction or sell your unwanted goods on eBay
- Get involved in our annual PBC Day held on the second Sunday in September

3. Get your employer involved

Ask us how your employer or the employer of someone you know could:

- Work in partnership with us or sponsor us?
- Donate time, funds and resources?
- Enable you or others to make donations from earnings, or company/personal pension plans, that are free of tax?
- Help you to fundraise at work, by holding cake sales and dress down days?
- Match your fundraising total, or display our collection boxes?

We are five times more likely to be successful in a funding bid if an employee recommends us, so please ask your friends, family, and anyone else you know to ask this question: does their organisation give to charity?