

What is PBC?

Primary Biliary Cholangitis is a progressive autoimmune condition that affects the liver.

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-active 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:

An international helpline

Information packs for newly diagnosed patients

Compendium - “Living with PBC”

Self-management app (iOS and android)

Self-management workshops and webinars

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

Information leaflets for Healthcare Practitioners

Multilingual Website

UK-wide Volunteer Network

Facilitating research projects

Local members’ meetings

Peer to peer support via Health Unlocked

Raising awareness amongst the general public and throughout the medical professions

Just £5 per month provides all of these services for one PBC patient.



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The **PBC Foundation** is a UK-based International charity providing **help**, **support** and **information** to those affected by PBC.

Primary Biliary Cholangitis (PBC), formerly known as Primary Biliary Cirrhosis, is an **autoimmune condition** that affects the **liver**. Simply, the immune system starts an attack on bile duct cells in the liver. PBC has no cure and is the biggest single reason for liver transplant in adult females in the UK, accounting for almost 10% of all liver transplants in the UK.

The PBC Foundation has over 12,000 registered service users in 76 countries around the world.

 **foundation**
support for life

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 charity run by a small core staff, aided by a network of volunteers and governed by a board of directors. The Foundation is supported by some of the finest hepatologists in the UK and around the world.

Aims and Objectives:

To reach and support every PBC patient

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

To improve the quality of life for those affected by PBC

To find a cause and a cure for PBC

To provide a free service to those in need

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 financial assistance or 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?