



Understanding PBC



PBC CARE

CONVERSATIONS | AWARENESS | RESOURCES | EMPOWERMENT

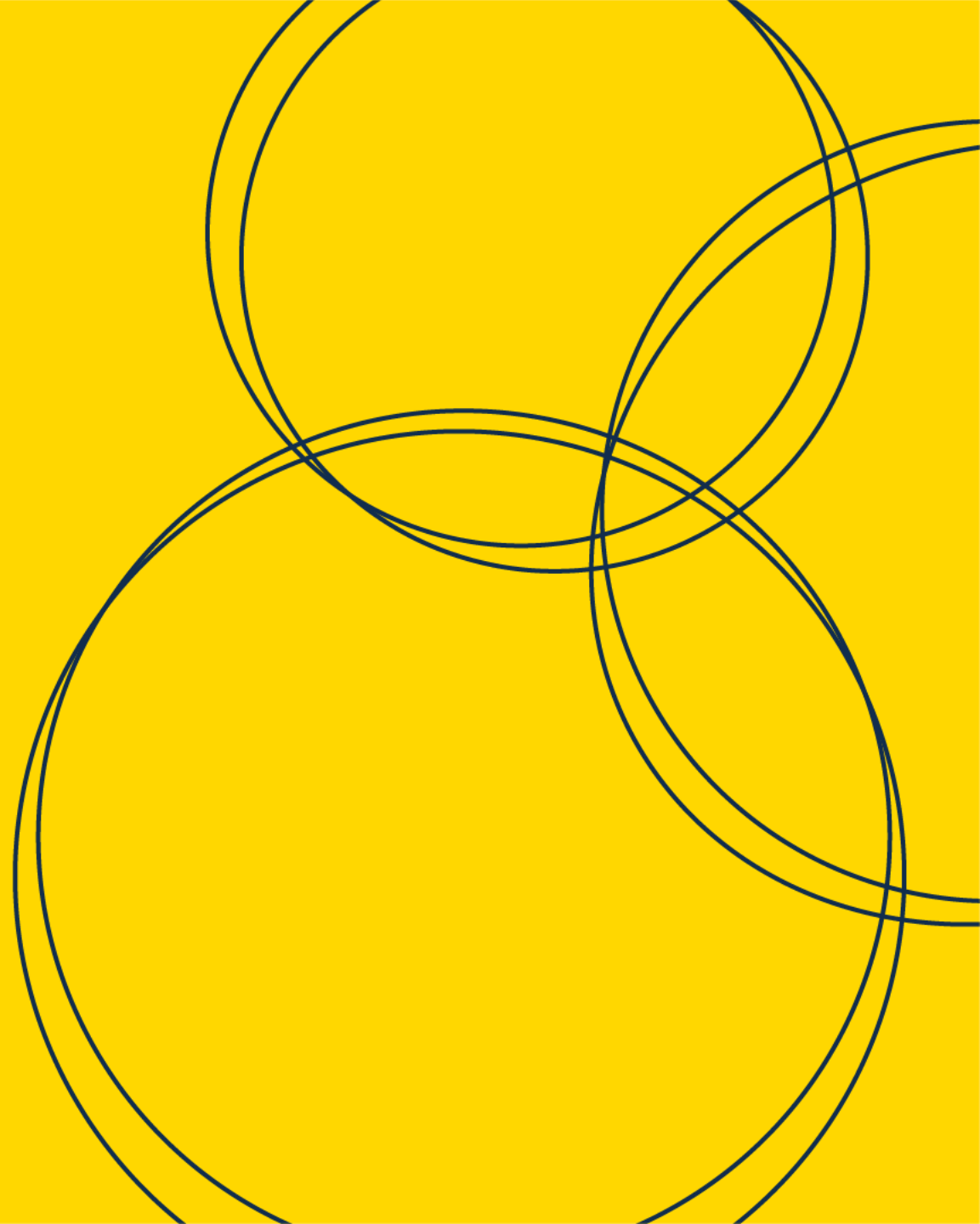
These materials have been developed by Ipsen with instrumental contributions in concept development and review from the following patient organizations: ALBI España, AMAF aps ets, Australian Liver Foundation, Casa Hunter, Deutsche Leberhilfe, PBC Canada, PBC Föreningen, PBC Foundation.

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Understanding PBC: Getting to know your PBC



What we will cover in getting to know your PBC

01

What is PBC?

02

Why does PBC happen?

03

Who is affected by PBC?

04

What are the goals for managing PBC?





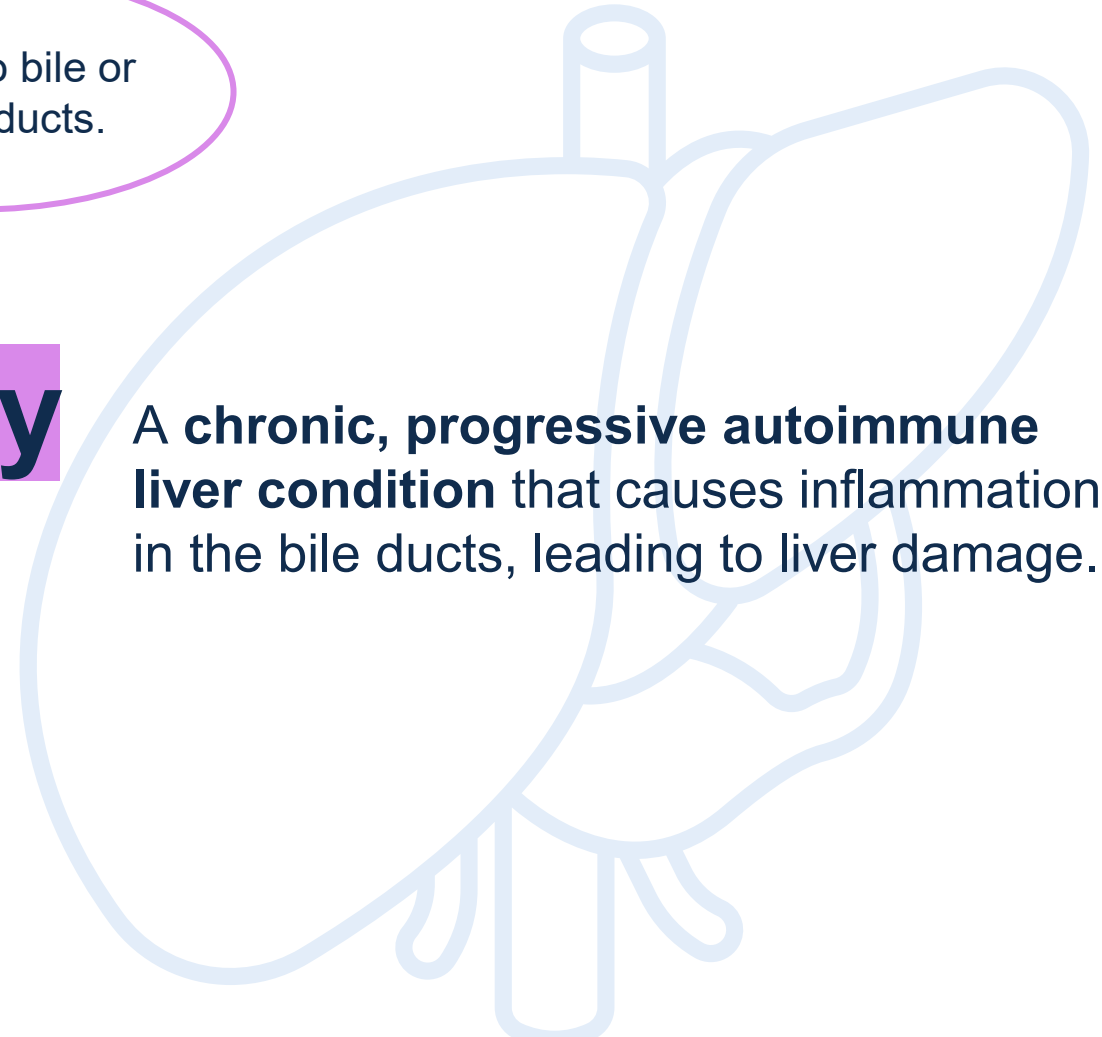
The main or first cause of something, rather than being caused by another condition.

Related to bile or the bile ducts.

What is **primary** **biliary** **cholangitis** (PBC)?

Inflammation (swelling and irritation) of the bile ducts.

A chronic, progressive autoimmune liver condition that causes inflammation in the bile ducts, leading to liver damage.





Words You Might Hear and What They Mean

Chronic	A condition or symptoms that are long-lasting or ongoing, sometimes for months of years.
Progressive	Gets gradually worse over time.
Autoimmune	When the body's immune system mistakenly attacks its own healthy cells.
Bile ducts	Small tubes that carry a fluid called bile from the liver to the small intestine.
Bile	A fluid produced in the liver that helps digest fats, absorb vitamins and remove waste from the body.
Inflammation	Swelling and irritation that can cause pain and redness in the body.
Liver	A large organ in the body that helps process food, remove toxins and store energy.



Why does PBC happen?

The body's immune system mistakenly attacks the bile ducts

The bile ducts become damaged, which causes bile to build up in the liver

This build-up of bile can damage the liver over time



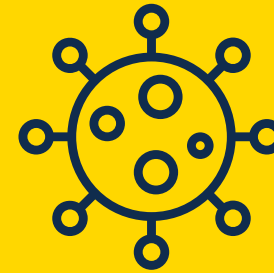
Researchers aren't exactly sure how or why PBC happens, but it is thought to be a combination of:



Family history – PBC can sometimes run in families, so genes may play a role

Environmental risks – there may be other factors that contribute, but we don't know exactly what they are yet

What we do know is that **PBC is an autoimmune condition.**



This means the immune system, which normally protects your body from infections, mistakenly attacks the small bile ducts in your liver. **Over time, this can cause damage.**



Why does PBC happen?

The body's immune system mistakenly attacks the bile ducts.

The bile ducts become inflamed and blocked.

This build-up of bile can damage the liver.



Researchers don't know exactly what causes PBC, but they think it's a combination of genetic and environmental factors.



Words You Might Hear and What They Mean

Immune system	The body's defense system that fights off infections and illnesses.
Autoimmune	When the body's immune system mistakenly attacks its own healthy cells.
Genetic predisposition	A person has a higher chance of getting a disease because it runs in their family.
Gut microbiome	A community of bacteria and other microbes that live in your digestive system.

Environmental risks—there may be other factors that contribute, but we don't know exactly what they are yet.



This means the immune system, which normally protects your body from infections, mistakenly attacks the small bile ducts in your liver. Over time, this can cause damage.

What is PBC?
What causes PBC?
What are the symptoms of PBC?
How is PBC diagnosed?
How is PBC treated?



Who is affected by PBC?



9 out of 10
people living with
PBC are women

Mostly around **40–60 years of age**. Men can also be affected, often at a later, more severe stage.



Highest rates in
North America,
followed by Europe.

Lower rates in the Asian-Pacific region, but increasing, especially in Japan and China.

Mostly **non-Hispanic**
White people

Also seen in Black, Asian-American and other racial groups.



More common in
industrialized areas

Also in smokers, and in people who use products like nail polish and hair dye.





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Words You Might Hear and What They Mean



Prevalence

How common something is within a group of people or population.

Risk factors

Things that increase the chance of getting a disease or condition.

Statistics

Numbers and data that help show how common or rare something is.

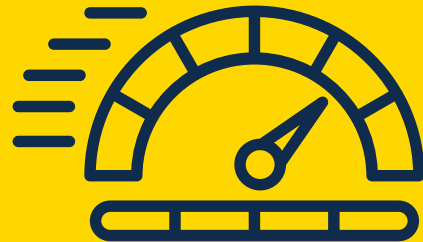


What are the main goals for managing PBC?

Slow down disease progression

- Slow down rate of liver damage
- Prevent progression to cirrhosis (scarring of the liver) and liver failure

Regular monitoring is important to assess how PBC is progressing and how well treatments are working.



Reduce symptoms to improve quality of life

Including fatigue, (itching) and bone problems

Certain treatments and lifestyle changes can help to reduce symptoms.



Ask your healthcare team for regular (guidelines suggest every 6 months) review of your PBC



What are the main goals for managing PBC?

Words You Might Hear and What They Mean

Treatment goals

The main things we hope to achieve with your treatment or care to improve health.

Disease progression

How a disease progresses over time. In some cases, a disease can start slowly and become more severe or complicated if not treated.

Symptom management

Ways to help reduce or control symptoms to help you feel better.

Prevention

Steps you can take to avoid getting sick or having a condition.

Treatment pathway

A clear plan that shows the steps and options for treating your condition.

Questions To Ask Your Healthcare Team

Example questions: Understanding PBC

What can I do to reduce fatigue and itching?

Can I prevent complications of PBC, and if so, how?

Why did I develop PBC?

What other organs might be affected by PBC (apart from the liver)?

How is PBC different from other liver diseases?

How can I monitor my PBC?

Are there any symptoms that mean my condition is getting worse?

When is my next appointment?



What questions could you ask your healthcare team?

Who in your healthcare team might you ask?

How comfortable do you feel talking to your healthcare team about these topics