

Glossary of Medical Terms Related to PSC

Acute-symptoms or conditions that occur suddenly and/or last a relatively short period of time (days or weeks, not months)

Anastomosis- a surgical connection between two structures. It usually means a connection that is created between tubular structures, such as blood vessels or loops of intestine.

Ascites- the build-up of fluid in the space between the lining of the abdomen and abdominal organs. Ascites results from high pressure in the blood vessels of the liver (portal hypertension).

Asymptomatic-presenting no symptoms of disease

Atypical- an unusual or irregular finding or presentation

Autoimmunity- refers to immune system overactivity, the body attacks and damages its own tissues (autoimmune disease). This is currently being studied as a factor contributing to development of PSC, along with genetic and environmental factors.

Bacterial cholangitis – bacterial infection in the bile ducts

Bile- a liquid produced by the liver, it contains cholesterol, bile salts, and waste products such as bilirubin. Bile passes out of the liver through the bile ducts and is stored in the gallbladder.

Bile ducts - the passages that carry bile from the liver to the intestines

Biliary system- having to do with the structures of the bile system. The biliary system creates, moves, stores, and releases bile to the small intestine

Calcifications- calcium build up in body tissue, causing the tissue to harden. This can be a normal or abnormal process and can be visible through imaging.

Cholangiocarcinoma- a rare cancerous (malignant) growth in one of the bile ducts

Cholangiography- the imaging of the bile ducts by x-rays aided by the injection of a dye

Cholangitis-inflammation of one or more bile ducts

Cholestasis- Reduction or stoppage of bile flow, disorders of the liver, bile duct, or pancreas can cause cholestasis, as can certain medications.

Choledocholithiasis – biliary stones (aka gall stones)

Chronic- refers to something that continues over an extended period of time. A chronic condition is usually long-lasting and does not easily or quickly go away. Chronic is the opposite of acute.

Cirrhosis- A late stage of scarring (fibrosis) of the liver

Comorbidity-Two health conditions that are present at the same time; co-occurring (ex. PSC and IBD)

Crohn's Disease- type of inflammatory bowel disease, Crohn's most commonly affects the end of the small bowel (the ileum) and the beginning of the colon, but it may affect any part of the gastrointestinal (GI) tract.

DEXA/DXA- A bone densitometry scan uses a very small dose of radiation to produce pictures of the inside of the body (usually the lower (or lumbar) spine and hips) to measure bone loss. Often used to evaluate osteoporosis.

Diagnosis of Exclusion- A diagnosis of a medical condition reached by a process of elimination, which may be necessary if presence cannot be established with complete confidence from history, examination or testing

Dys- a prefix used to convey the idea of being difficult, impaired or abnormal

Edema- swelling caused by excess fluid trapped in your body's tissues, often seen in the hands, ankles and feet

Epidemiology- the study of the distribution and determinants of health-related states or events

Endoscopy- - a nonsurgical procedure used to examine a person's digestive tract. Using an endoscope, a flexible tube with a light and camera attached to it, your doctor can view your digestive tract and perform certain procedures (ex. stent placement)

ERCP- (endoscopic retrograde cholangiopancreatography) is a procedure used to diagnose diseases of the gallbladder, biliary system, pancreas, and liver. The test looks "upstream" where digestive fluid comes from -- the liver, gallbladder, and pancreas -- to where it enters the small intestines.

Extrahepatic – situated or originating outside the liver

Fecal microbiota transplant (FMT) - the process of transplantation of fecal bacteria from a healthy individual into a recipient. This procedure is typically done via colonoscopy.

Fibrosis- scarring of the (liver) tissues in response to injury

Fibroscan- FibroScan is principally used to estimate the degree of liver scarring present (ie. stage of liver disease) It is a non-invasive device that assesses the 'hardness' (or stiffness) of the liver by measuring the velocity of a vibration wave (also called a 'shear wave') generated on the skin.

Genotype- your complete heritable genetic identity; it is your unique genome sequencing. However, genotype can also refer just to a particular gene or set of genes carried by an individual.

Graft- a piece of living tissue that is surgically transplanted.

Hepatic Encephalopathy (HE)- deterioration of brain function that occurs in people with severe liver disease, also called "brain fog" HE is caused when toxins that are normally cleared from the body by the liver accumulate in the blood, eventually affecting the brain.

Hepatomegaly- an enlarged liver

Hyper (prefix)-excessive or increased beyond normal

Hyperplasia-Increased cell production in a normal tissue or organ; may be a sign of abnormal or precancerous changes, or growth of completely normal cells

Hypo (prefix)-less than normal, deficient

Idiopathic- relating to or denoting any disease or condition which arises spontaneously or for which the cause is unknown

Immunosuppression- a condition in which the body's immune system is intentionally stopped from working, or is made less effective, usually by drugs, especially in order to help the body accept an organ that has been transplanted.

Inflammatory bowel disease (IBD)- an umbrella term used to describe disorders that involve chronic inflammation of your digestive tract. (ex. ulcerative colitis and Crohn's disease). Both ulcerative colitis and Crohn's disease can involve severe diarrhea, abdominal pain, fatigue and weight loss.

Interventional Radiology (IR)- minimally invasive, image-guided treatment of medical conditions that once required open surgery. IR utilizes ultrasound, X-rays, CAT scans, MRI scans or other innovative imaging methods.

Itis (suffix)-Refers to inflammation (ex. cholangitis, colitis)

Jaundice- a condition in which the skin, whites of the eyes and mucous membranes turn yellow because of a high level of bilirubin, a yellow-orange bile pigment. Jaundice has many causes, including hepatitis, gallstones and tumors

Liver Biopsy-A small sample of liver tissue obtained by inserting a special needle through the abdominal wall and into the liver. The tissue can then be examined for signs of damage or disease.

Lesion- a region in an organ or tissue which has suffered damage through injury or disease

Metabolic bone disease-umbrella term for any of several diseases that cause various abnormalities or deformities of bone (ex. osteoporosis- a disease in which the density and quality of bone are reduced)

Microbiome/Microbiota: The human microbiota consists of the 10-100 trillion symbiotic (involving beneficial or harmful interaction among cells) microbial cells harbored by each person, primarily bacteria in the gut; the human microbiome consists of the genes these cells harbor (Dr. Rob Knight)

Necrosis- death of cells or tissue through disease or injury.

Nodule- a growth or lump that may be malignant (cancer) or benign (not cancer).

Pathology- the study of the causes and effects of disease or injury.

Patient Reported Outcome (PRO)- a PRO is an outcome directly reported by the patient and pertains to the patient's health, quality of life, or functional status associated with health care or treatment. This places patients at the center of health care research and clinical care evaluation.

Phenotype- actual observed properties, characteristics or traits (ex. height and hair color)

Prebiotics- a non-digestible food ingredient that promotes the growth of beneficial microorganisms in the intestines.

Probiotics- live microorganisms that, when administered in adequate amounts, confer a health benefit on the host by improving or restoring the gut flora

Plasty (suffix)-surgical procedures that repair, replace, restore or improve the body

Portal hypertension- an increase in the pressure within the portal vein (the vein that carries blood from the digestive organs to the liver). The increase in pressure is caused by a blockage in the blood flow through the liver.

Pruritus- localized or generalized itching, a prevalent and often distressing symptom of cholestasis.

Registry- a standardized database of medical data that can include information such as diagnosis, family history, medications, surgeries, quality of life, and test results. Often registries are disease-specific and data can be either patient reported or physician reported.

Rejection (transplant) - occurs when the immune system of the recipient of a transplant attacks the transplanted organ or tissue. This is because a normal healthy human immune system can distinguish foreign tissues and attempts to destroy them, just as it attempts to destroy infective organisms such as bacteria and viruses.

PSC Partners Patient Registry: a patient-driven, patient-reported registry that serves to facilitate PSC research and clinical trials. www.pscpartnersregistry.org

Sclerosis- pathological condition involving tissue swelling (inflammation), scarring, and hardening. This process causes the destruction of the bile ducts inside and outside of the liver.

Splenomegaly-abnormal enlargement of the spleen

Stent-short narrow metal or plastic tube often in the form of a mesh that is inserted into the lumen (channel) of an anatomical vessel (artery or bile duct) to keep a previously blocked passageway open

Stricture-An abnormal narrowing of a tube or canal such as the bile duct (often from inflammation, cancer, or scar tissue) this narrowing can slow or obstruct the flow of body fluids.

Transient Elastography-(Fibroscan)- a non-invasive test that assesses the hardness (or stiffness) of the liver by measuring the velocity of vibration waves.

Ulcerative colitis- This Inflammatory Bowel Disease causes long-lasting inflammation and sores (ulcers) in the innermost lining of the large intestine (colon) and rectum. PSC is often associated with ulcerative colitis.

Xanthomas-fatty irregular yellow patches or nodules containing lipid-filled cells occurring on skin (eyelids, neck, back) or internal tissue, often associated with disturbances of lipid metabolism

Helpful Website:

NIH Clinical Research Trials Terms: <https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms>

Medical Abbreviations Related to PSC

5-ASA: 5-aminosalicylic acid

6-MP: 6-mercaptopurine

AIH- Autoimmune hepatitis

ALP- Alkaline phosphatase

ALT- Alanine aminotransferase

AST- Aspartate aminotransferase

BMD – bone mass density

Bx- Biopsy

CA 19-9: Carbohydrate antigen 19-9

CB or CBC: Complete blood count

CC or CCA: Cholangiocarcinoma

CD: Crohn's disease

CEA: Carcinoembryonic antigen

Dx: Diagnosis

ERCP: Endoscopic retrograde cholangiopancreatography

ESLD: End stage liver disease

FISH: Fluorescent in-situ hybridization

FNA: Fine needle aspiration

GGT: Gamma-glutamyltranspeptidase

HA: Hepatic artery

HE: Hepatic encephalopathy

IBD: Inflammatory bowel disease

IgG4: Immunoglobulin that is typically high in PSCers

INR: International normalized ratio

IV: Intravenously

LDLT: Live donor liver transplant

LFT: Liver function test

LT: Liver transplantation

MRCP: Magnetic resonance cholangiopancreatography

NIH: National Institutes of Health

NORD: National Organization of Rare Diseases

ORDR: Office of Rare Disease Research

pANCA: Pernicular antineutrophil cytoplasmic antibodies

PBC: Primary biliary cholangitis

PSC: Primary sclerosing cholangitis

PTT: Prothrombin time

QOL: Quality of life

RUQ/URQ: Right upper quadrant

SMAC: Scientific/Medical Advisory Committee of PSC Partners Seeking a Cure

Tx: Transplant

UC: Ulcerative colitis

UDCA: ursodeoxycholic acid, Urso, ursodiol

