

WHERE CAN I FIND SUPPORT AND INFORMATION?

PSC Partners Seeking a Cure is a 501(c)3 nonprofit foundation that endeavors to find a cure for primary sclerosing cholangitis. Please consider joining our mailing list at:

www.pscpartners.org

An online PSC support group was established in 1998. This is a message board (forum) on Yahoo/Health, where PSC patients and caregivers can exchange information and lend support/advice to one another:

<http://health.groups.yahoo.com/group/psc-support/>

In the United Kingdom, there is a similar group that publishes a newsletter and holds an annual meeting in Oxford with Dr. Roger Chapman, a leading PSC expert:

www.psc-support.demon.co.uk

There is also a parents' support group, especially helpful for parents of young children, as PSC presents itself differently in pediatric patients, and is treated accordingly. This group is found at:

<http://health.groups.yahoo.com/group/pscmoms/>

Pre-teen kids and teens with PSC can get acquainted with others through a new online board:

<http://health.groups.yahoo.com/group/psckids-support/>

For post-transplant PSC patients, there is a support group with discussions based on the special needs of being post-surgical, immunosuppressed, and their "at-risk" status. You may join this group at:

<http://health.groups.yahoo.com/group/Livertx-PSC/>

For social networking, sharing, and learning about living with PSC in your 20s and 30s, check out Facebook.

To join the group, Log into Facebook at www.facebook.com and then type in:

www.facebook.com/group.php?gid=39847120173

For PSCers and caregivers in Israel, there is an Israeli Facebook group. Log into Facebook at www.facebook.com and then type in:

<http://www.facebook.com/group.php?gid=33277534316>

For information on:

our local/regional support groups

our free quarterly newsletter

our annual conference for PSC patients and caregivers

our other brochures:

Living with PSC and Diagnosing PSC

www.pscpartners.org

A PSC Literature web site was developed in 2004 to provide PSC patients and caregivers easy access to a vast body of information concerning PSC and allied illnesses:

www.psc-literature.org

For detailed information on inflammatory bowel disease, please visit the Crohn's and Colitis Foundation of America (CCFA) web site at:

www.cdfa.org

FOR MORE INFORMATION, OR TO HELP FUND THE CURE:

Visit our website at:

www.pscpartners.org

or contact Ricky Safer by e-mail at:

Contactus@pscpartners.org

or send a tax-deductible donation to:

PSC Partners Seeking a Cure

5237 S. Kenton Way

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To order more brochures, please write to us at:

Brochures@pscpartners.org

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primary sclerosing cholangitis

medications

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SEEKING A CURE

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PSC & MEDICATIONS

Primary sclerosing cholangitis (PSC) is a cholestatic liver disease, meaning that bile flow from the liver to the small bowel is slow or stagnant. Accumulation of toxic bile acids in the liver can result in damage to liver cells, and increase potential for cancer development in the bile ducts and colon. Medications used for PSC include Urso (which stimulates bile flow and protects liver cells against toxic bile acids), Cholestyramine (a bile sequestering agent which treats pruritus (itching)), or compounds that stimulate bile acid transport and metabolism, such as Rifampin (which may also address pruritus).

URSODEOXYCHOLIC ACID

(Ursodiol, Urso Forte, UDCA, URSO-250, Actigall, Ursofalk)

Urso is a popular medication used for patients diagnosed with PSC (primary sclerosing cholangitis). Originally prescribed for the treatment of gallstones, Urso has been shown to help bile acids travel through the body with greater ease. In addition, some anti-inflammatory properties have been noticed. Urso helps to fight toxic bile acids that build up in the liver cells. In the United States, Urso is available under different trade names such as Actigall (typically 300 mg. capsules), Urso (typically 250 mg tablets), and Urso Forte (typically 500 mg tablets.) Urso Forte and Urso 250 are the only FDA approved treatment for patients with PBC (primary biliary cirrhosis), a disease similar to PSC. Another variation of Urso is available in Australia under the name Ursofalk (250 mg capsules). Ursofalk is also available in a liquid formulation for pediatric patients.

Ursodiol is typically prescribed in dosages of 15-30 mg/kg a day. The benefit of high-dose Ursodiol is questionable, and a recent study suggests that high doses may actually be detrimental. For this reason, most hepatologists prescribing Ursodiol today will use doses in the range of 15 to 20 mg/kg a day.

To calculate your dose (based on pounds), multiply your daily dose in mg by 2.2, and divide by your weight in pounds (e.g., 2.2 x 1200 mg/180 lb = 14.6 mg/kg).

Another unproven, but suggested benefit of Ursodiol may be reduction in risk of colon cancer and cholangiocarcinoma.

RIFAMPIN

Rifampin (Rifampicin) is an antibiotic mostly used for the treatment of tuberculosis. However, because it activates receptors in the gut and liver, it has also been shown to help relieve pruritus (itching). Urso and Rifampin generally work well together. However, Rifampin may cause changes in other medications you are taking and alter the way they react in your system. Make sure your doctor is aware of all other medications you are taking along with Rifampin, in order to avoid any possible conflicts.

CHOLESTYRAMINE

Cholestyramine (Questran) is used to treat high cholesterol and also has been proven effective in combating pruritus due to bile blockages. Cholestyramine is not absorbed in the bloodstream; it remains inside the gut until excretion. Cholestyramine and Urso cannot be taken together, as this will interfere with Ursodiol absorption. The general recommendation is to stagger doses of the two medications at least four hours apart. It has an unfortunate consistency (frequently likened to “drinking liquid sand”), but there are acceptable methods to make it more palatable.

Some of these include: mixing with apple-sauce, apple juice, Sunny-D®, etc. Basically, use any cool or cold liquid or smoothie (heating can inactivate the drug).

ANTIBIOTICS

Oral Vancomycin

There are some research studies in progress treating PSC patients with oral Vancomycin to see if there is a therapeutic benefit.

Ciprofloxacin

One of the major challenges in PSC is the occurrence of bacterial cholangitis; a bacterial infection of the biliary tree. Such infections are often associated with chills and fever, right upper-quadrant pain, dark urine, pale stools, nausea and vomiting. If left untreated, these biliary infections can rapidly progress to sepsis and death. Antibiotics used to treat these infections include Ciprofloxacin (Cipro).

ABC Regimen

Repeated cholangitis attacks are sometimes managed by a rotating antibiotic regimen often termed “ABC”, in which patients take Augmentin, Bactrim DS, and Cipro alternately to minimize development of bacterial antibiotic resistance.

Other

Endoscopic procedures such as ERCP can potentially introduce bacteria into the bile ducts. Many centers prescribe antibiotics for patients undergoing ERCP to prevent this complication. However, there are conflicting results concerning the efficacy of such prophylactic antibiotics in prevention of post-ERCP pancreatitis.

CORTICOSTEROIDS

Corticosteroids, and other immunosuppressants, have been found to be ineffective in favorably altering the course of classic PSC. However, it should be emphasized that there may be sub-groups of patients who may show excellent response to corticosteroids. Thus, it is essential to identify these patients as early as possible in the disease course. These patients include those with autoimmune hepatitis (AIH)/primary sclerosing cholangitis (PSC) overlap syndrome, and patients with IgG4

sclerosing cholangitis resembling autoimmune pancreatitis (AIP). The latter group is estimated to comprise about 7-10% of patients with PSC. The AIH/PSC overlap syndrome tends to be more common in children.

ADVERSE EFFECTS

Medications are rarely free of side effects; some side effects may be mild, others severe. When prescribed any medication, you should read the drug safety sheet provided and become familiar with all potential adverse effects of the medication. Consult your doctor immediately if you experience any of the symptoms described in the drug safety sheet(s).

NON-PRESCRIPTION REMEDIES

There are very few large, scientifically controlled, peer reviewed trials for alternative therapies (non-prescription remedies). The Food and Drug Administration does not regulate the manufactured quality of herbal supplements; herbal labels usually do not indicate dosage recommendations for specific conditions. PSC and its related diseases are complicated and we laymen just don't know enough – some remedies may even be unsafe, and further damage your liver.

PSC Partners Seeking a Cure believes that medical professionals should be the primary source of information for treating your PSC. Treatment tested over the years has worked for many patients. We believe it is prudent to be cautious with over the counter remedies, vitamins/minerals, and herbals. There may be interactions with other medications, and sometimes even between herbals and vitamins. Always ask your doctor when you make any change in your health routine and what you are doing to manage your disease. You might want to go to <http://medlineplus.gov/> to look at these two sections: Drugs, Supplements and Herbal Information and also Complementary and Alternative Therapies.