

THE DUCT

A Monthly Newsletter for the PSC Community

October 2019

Patient Registry

2020 Conference

Donate Now

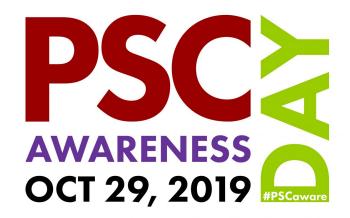
In this issue: <u>PSC Awareness, PFDD Date Change, Annual Conference, Living with PSC Podcast #15 - Drug & Clinical Developments, Clinical Trials, Patient Blog, ICD-10 Progress, Matching Gifts</u>



Why is Dr. Aliya Gulamhusein smiling? It could be because her presentation, along with all presentations from the 2019 PSC Partners Annual Conference, are available on our website.

Check them out.

PSC Awareness Day is Oct. 29 HELP US SPREAD THE WORD



HELP MAKE PSC AWARE ESS

HERE'S HOW:

• TAG PSC PARTNERS:

We are posting PSC facts daily on the PSC Partners Facebook (@PscPartnersSeekingACure), Twitter (@PSCPartners), and Instagram (psc.partners) pages. Please share them on your social media pages, and use the #PSCaware, and tag PSC Partners.

• FRAME FACEBOOK PHOTO:

Update your Facebook profile picture with our <u>Awareness Day Frame</u>. Search for PSC Awareness 2019, and click *Use as Profile Photo*. You can schedule the frame to by removed on November 1, 2019.

UPDATE PROFILE PHOTOS:

Use the 2019 PSC Awareness logo (pictured above or below) as your profile photo on other social media outlets and when posting other things about PSC and PSC Partners during the week leading up to PSC Awareness Day.

• POST VIDEO OF YOURSELF:

Spread awareness about PSC Partners by posting a short video of yourself on social media answering the question, "What is one thing you wish people knew about PSC?" Videos should be posted on October 29. Be sure to tag PSC Partners and use #PSCaware.

• WEAR PSC PARTNERS GEAR:

On October 29, wear PSC Partners gear. Post a photo of yourself, tag PSC Partners, and include #PSCaware.

Want other ideas of things to post? Check out the <u>PSC Awareness Page</u> on our website.

WATCH SOCIAL MEDIA SITES ON OCT. 29TH FOR THE RELEASE OF A VERY SPECIAL VIDEO!



Date Change for PFDD MEETING Meeting Now: OCT. 23, 2020



The date for the PSC Partners' Patient-Focused Drug Development (PFDD) meeting has changed to 10/23/2020. Your participation is very important. So, please update your calendars.

The externally-led PFDD meeting will be held in Washington, D.C., in partnership with the FDA's Center for Drug Evaluation and Research (CDER) Office.

PSC patient and caregiver participation is vital to the success of the meeting. Watch our newsletter, social media, and website for more information about how to get involved.

Mark Calendars for 2020 Conference April 24-26th



If you've already marked your calendars for the 16th Annual PSC Partners Conference in Denver, April 24-26, 2020, let us be the first to give you a round of applause!

The conference, which draws patients and caregivers (spouses, partners, parents, siblings, and friends), wouldn't be the same without you.

DON'T MISS IT!

We're working on registration materials and the agenda, including a Friday outing to Red Rocks.

We'll let you know when registration is open.







Living with PSC Episode #15: DRUG AND CLINICAL DEVELOPMENT

In this <u>episode</u> of Living with PSC, Niall McKay talks with Co-Chair of PSC Partners Medical Advisory

Committee Dr. Christopher Bowlus, Division Chief of Gastroenterology & Hepatology and Professor at UC Davis School of Medicine, about drug and clinical development in the search for treatments and a cure for PSC.

Click here to listen to the podcast.

The Living With PSC podcast series is moderated by Media Producer Niall McKay. Each month, this podcast explores the latest research and knowledge about PSC. From patient stories to the latest research updates from PSC experts to collaborations that are necessary to find better treatments and a cure, this podcast has it all! Click here for a complete list of episodes as well as past PSC Partners blog posts.

DO YOU QUALIFY FOR A CLINICAL TRIAL?

The following clinical trials are recruiting PSC patients. Take a look at the criteria to see if you might qualify.



• CymaBay is currently recruiting for: A Phase 2, Randomized, Double Blind, Placebo Controlled, Multiple Center Study to Evaluate the Safety, Tolerability, and Efficacy of Seladelpar Administered for 24 Weeks in Adult Patients with PSC. For more information, please click here.



• Gilead Sciences is currently recruiting for: A Phase 3, Randomized, Double-Blind, Placebo-Controlled Study Evaluating the Safety, Tolerability, and Efficacy of GS 9674 in Subjects with Primary Sclerosing Cholangitis Without Cirrhosis. For more information, please click here.

PSC Partners Blog Spot

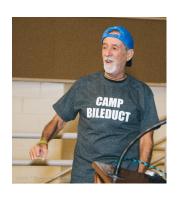
INFORMATION CAN BE HARMFUL TO YOUR HEALTH

by Tim Wholey

"Whoa! What the heck is this guy talking about? Information is power, isn't it?"

PSCer Tim Wholey clarifies his chosen blog title in the article he wrote for the PSC Partners' Blog.

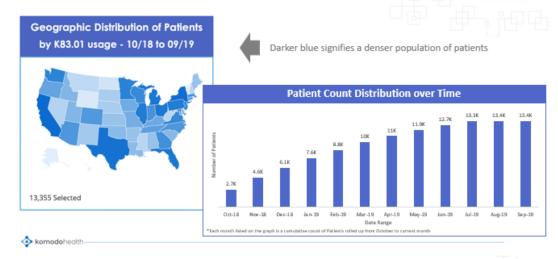
Check it out.



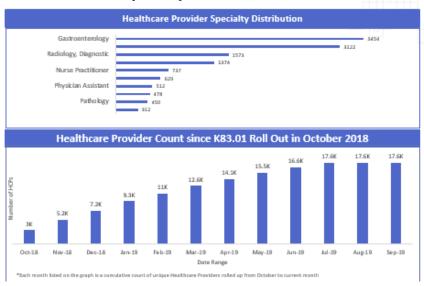
Doctors are Making Switch to K83.01

The word is getting around that the new PSC ICD10-CM code is K83.01.

Patient Counts and Geographic Distribution since K83.01 Roll Out



Healthcare Provider Counts & Specialty Distribution since K83.01 Roll Out



Keep the momentum going by reminding your healthcare providers to change the PSC ICD-10 code to K83.01. Remember, use of the proper code facilitates identification for trials, robust epidemiological and natural history studies, early and better identification and assessment of therapeutic outcomes, and more.

Matching Gift Programs Make Donations Go Twice As Far

Many companies match employee gifts to charitable organizations. If your place of work matches charitable donations, don't forget to tell them about your gift to PSC Partners. This is a great way to multiply the impact of your donation!

Check out our <u>donation page</u> for more information.



The mission of PSC Partners Seeking a Cure is to provide education and support to PSC patients, families and caregivers and raise funds to research causes, treatments and cures for primary sclerosing cholangitis.

PSC Partners Seeking a Cure (303) 771-5227 | contactus@pscpartners.org | pscpartners.org 6900 E. Belleview Ave., Ste 202, Greenwood Village, CO 80111









