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THE DUCT

A Monthly Newsletter for the PSC Community

May 2018

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PRIMARY SCLEROSING CHOLANGITIS NOW HAS ITS OWN ICD-10-CM CODE!



Researchers have long complained about the absence of a PSC-specific code for conducting epidemiological studies. Without knowing how to answer the questions, "Who has PSC? When was diagnosis made and where are these PSC patients?" only estimates could be made about determinants of PSC in defined populations. With a rare disease like PSC, knowing the location and diagnostic details of every patient is extremely important for proper research. And this is only one of the important functions of an ICD-10-CM code!

What is an ICD-10-CM code?

ICD-10-CM stands for International Classification of Diseases,

10th Revision, Clinical Modification. It is a classification system used by the United States for translating the words of a diagnosis into a standardized code of letters and numbers to identify a certain diagnosis, procedure, symptom, etc. It is based upon ICD-10, a coding classification system developed by The World Health Organization (WHO), used worldwide to do the same.

These codes are the lifeblood of many aspects of the healthcare system in the US, and are used by every healthcare entity including doctors, therapists, hospitals, and urgent care centers. For example, if a patient has acute appendicitis, it doesn't matter where they are seen or treated, the same diagnosis code (K35.80) will be used by everyone.

What does this have to do with PSC?

Believe it or not, until now, PSC has never had its own code. In the past, PSC was grouped together with all other types of cholangitis under a generic diagnosis code of K83.0. This made it very difficult to do any analysis of data for comparison of outcomes specific to PSC patients.

This is about to change. Last fall, we made a presentation to the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare and Medicaid Services (CMS) to request a specific code for PSC. After working with the ICD-10 Coordination and Maintenance Committee for the last seven months, we were recently informed that the Committee has approved our request for a specific code for PSC at K83.01. We will no longer share a code with any other diagnosis or condition as of October 1, 2018!!



K83.01

Although the difference between K83.0 and K83.01 doesn't seem like too big of a change, this is a BIG deal! This one little number

gives PSC its own disease-specific code rather than being included in the catch-all cholangitis code. Having a PSC-specific code will help healthcare providers to identify PSC in their patients and recommend appropriate treatment options, and will reduce confusion in the billing process. It will also lessen the risk of misdiagnosis and improper treatment of PSC patients.

Additionally, a disease-specific code will facilitate PSC research efforts, because researchers will be able to separate PSC data from other types of cholangitis included in the present catch-all code. PSC Partners is extremely excited about the ICD-10 Coordination and Maintenance Committee's decision to issue a disease-specific code for PSC. We believe that having a unique code for PSC will go a long way towards addressing the unmet needs of PSC patients.

This wonderful development would not have been possible without the advice, dedication, and expertise of Trish Stoltzfus. Trish is the mother of a PSCer and a professional coder who has volunteered for PSC Partners for many years. Trish has worked tirelessly in the past year to make a PSC-specific code a reality, and it wouldn't have happened without her. From the bottom of our hearts - thank you, Trish!

Conference Reminders & Updates

Saturday Night's Theme: Luau!

When you're packing for the 2018 conference, don't forget to bring some tropical attire! As returning conference attendees know, Saturday night is a celebration of our amazing community, and a much-needed chance for lightheartedness and fun after a full day of educational sessions. This year, our celebration will take the form of a Luau, and we encourage everyone to show their PSC Partners spirit by coming dressed in their tropical garb of choice. Creativity and humor are appreciated - the tackier the better!



If this will be your first PSC Partners conference, you can get a better idea of our Saturday conference celebration by looking at photos from 2017, which are available [here](#).

Deadline Approaching: Regular Registration for the Annual Conference Ends on May 28th

If you have been putting off signing up for our annual conference, now is the time to register and book your hotel room! The following dates and prices apply for conference registration:

- Regular Registration 4/09/2018 - 5/28/2018: \$220 per person
- Late Registration 5/29/2018 - 6/09/2018: \$250 per person



If you haven't made your hotel reservations yet, there are still discounted rooms available at the Sheraton Grand Sacramento Hotel, but they are filling up quickly. [Click here](#) to book your room and take advantage of our special room rate and subsidy. For all information about the discounted room rate and the room subsidy, please [click here](#).

**Enjoy Some Time in the Limelight:
Become a 2018 Community Conference Sponsor**
(psst...the karaoke sponsorship is still available!)



Even if you'd rather not get on stage and belt out all the hits from decades past, you can still be a rockstar by supporting the 2018 conference as a community sponsor. [Click here](#) to see the various community sponsorship levels that are available, and know

that your sponsorship will help us subsidize half of the cost of each and every attendee's registration. Thank you for your support!

News, Education, and Advocacy

PSC Partners Presents its First EASL Award at the 2018 International Liver Congress in Paris



PSC Partners was incredibly honored to present its first research award at an EASL (European Association for the Study of the Liver) meeting to researcher Dr. Knut Stokkeland in Sweden for his fascinating work on

the potential influence of statins on the disease course of PSC. [Click here](#) to read the award-winning abstract. Congratulations, Dr. Stokkeland!

PSC Partners also hosted a booth at the ILC, and we were incredibly encouraged by the dedication, intelligence and compassion of the many hepatologists that we met. Their commitment to the study and treatment of liver disease, in all its forms, is a great source of hope to us all.



Important ILC Research Updates

To view digital materials presented at the ILC that are open to the public, [click here](#). Of particular interest to PSC patients and caregivers, NGM Bio presented some very exciting information about its Phase 2 study of NGM282 in patients

with PSC. The data presented shows statistically significant improvements in hepatic injury and fibrosis, as well as significant reductions of bile acid synthesis and serum bile acids. To read more about this promising study, [click here](#).



PSC Podcast Episode 2- Dr. Christopher Bowlus: Diet & Emerging Treatments

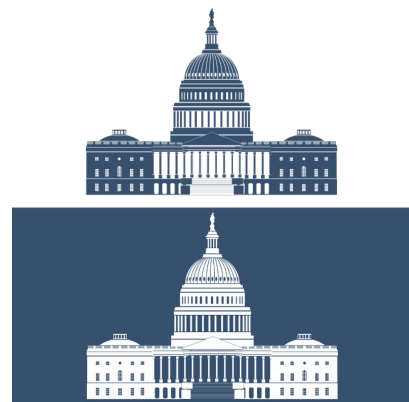
In the second episode of Living with PSC, Niall McKay interviews Dr. Chris Bowlus about diet and some of the emerging treatments for PSC.

Dr. Bowlus is a Professor and Division Chief of Gastroenterology and Hepatology at the University of California, Davis, and is co-host of our 2018 Conference in Sacramento. He is also co-chair of PSC Partners' Scientific/Medical Advisory Committee and scientific head of the PSC Partners Registry.

[Click here to listen!](#)

Liver Capitol Hill Day 2018: Perspectives from 2 PSC Partners Advocates

On April 18, 2018, The American Association for the Study of Liver Disease (AASLD) organized an event (Liver Capitol Hill Day) in which liver transplant patients, physicians and patient advocates visited our nation's capital to impart knowledge about liver diseases and advocate for policies that benefit those affected by liver disease. PSC Partners Seeking a Cure was thrilled that two members of our community, Dr. Willie McKinney and Dr. Lalit Gupta, were able to attend this important event and advocate on behalf of PSC patients and caregivers. [Visit our blog](#) to read about their experiences.



Roanoke College Features PSC Patient Lindsey

Nanz in Honor of National Donate Life Month



Lindsey and Sharon Nanz are beloved members of the PSC Partners community, and we were thrilled to see that Lindsey was recognized by Roanoke College in an article for National Donate Life Month. [Click here](#) to read her story of navigating life, college, and two liver transplants. Thank you for sharing, Lindsey!

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.

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