

The mission of PSC Partners Seeking a Cure is to provide education and support to PSC patients, families, and caregivers, as well as to raise funds to research causes, treatments, and a cure for primary sclerosing cholangitis (PSC). Founded in 2005, PSC Partners Seeking a Cure is a 501(c)(3) nonprofit organization. Numerous programs give support to patients, caregivers, families, and friends, educate patients and the medical community about PSC, and drive ground-breaking research in the search for a cure.

PSC Partners Seeking a Cure 2020 Accomplishments

Making Our Voices Heard: Patient Focused Drug-Development Forum

"What an incredibly professional, moving, and informative meeting. I am at a loss of words to tell you how emotional it was to listen to everyone's stories, and I truly feel that the PSC voices were heard loud and clear today!"

PSC Partners conducted the successful [Making Our Voices Heard: Patient-Focused Drug Development Forum \(PFDD\)](#). This once-in-a-lifetime, virtual event educated FDA, drug development leaders, and researchers about the vital need for effective treatments and a cure for PSC. The Forum was a patient-driven initiative through and

through. The PSC community's financial support of this project was so extensive that the funds completely covered all meeting expenses.

PSC Partners Conference Webinar Series

Over the past year, we conducted seven informative [webinars](#), in lieu of our postponed, in-person 2020 Conference, to ensure that our U.S. and global communities stay informed and educated about PSC, treatments, PSC research, and more. This initiative was so successful, with recordings receiving more than 5,000 views so far, that it has prompted the development of a new virtual **PSC Partners Learning Series and Collaboration Hub** for international medical providers, researchers, patients, and caregivers. This exciting initiative is in the planning stage, and will begin soon.

Total Grants Awards Exceed \$4 Million

Every year, on the recommendation of the Scientific/Medical Advisory Committee (SMAC), the PSC Partners' Board of Directors reviews all applications and supports the most promising PSC-related studies. In 2020, we announced the funding of seven international [studies](#), plus three more in conjunction with our affiliate [PSC Partners Canada](#). This brings our funding total to more than \$4 million.

PSC Partners Patient Registry



The PSC Partners Patient Registry was initiated in response to the difficulty of locating PSC patients and PSC data to conduct research on our rare disease and to empower the patient voice. Since its creation, more than 1,700 confirmed PSC patients have added their de-identified information. In 2020, the [PSC Partners Registry](#) was upgraded and enhanced to meet the changes in PSC research and to provide a more interactive platform for registry participants. The increased capabilities of this new version will accelerate research and clinical trials. We also

experienced an unprecedented surge in the number of Registry participants over the past year, evidence of the eagerness and readiness of the PSC community to participate in PSC research.

PSC Peer-to-Peer Virtual Support

"I was so happy to be part of the group on Zoom. This was the first time I had interaction with people with PSC."

Early in the COVID-19 pandemic, PSC Partners created virtual gatherings for the PSC community. The purpose of these support groups, called ZoomRooms, is to continue to respond to the social and emotional needs of our community despite the postponement of the last two PSC Partners Conferences and the effects of separation due to the pandemic. ZoomRooms are for teen PSCers, adult PSCers, spouses/caregivers, and parents of pediatric, teen,

and adult patients. The program has been so successful that it will continue through 2021 and beyond.

One of 30 Nonprofits Selected for CZI Rare As One Initiative

We were thrilled and honored to be one of 30 patient-led organizations chosen for the Chan Zuckerberg Initiative's Rare As One Project, which was designed to establish patient-driven collaborative research networks with international researchers, identify gaps in PSC research, and stimulate specific research towards closing these research gaps. The 30 grantee organizations are working together with the guidance of the Rare As One science team, which has been providing us with rich resources and tools to achieve these goals. Over the past year, PSC Partners has participated in numerous educational webinars and nonprofit gatherings. These opportunities will continue into 2022.

Launched a Specialist Map

PSC Partners created a [dynamic specialist map](#), making it easier for our community to locate PSC healthcare providers near them. This impactful tool was launched in late 2020 with assistance from Komodo Health, a healthcare data management company. This partnership also has helped us identify and communicate directly with more PSC physicians, nurse practitioners, physician assistants, and researchers.

PSC and COVID-19 Survey

We developed the only PSC-specific [COVID-19 Survey](#), which was launched as soon as the COVID-19 pandemic began in the spring of 2020. Aggregated information will be shared publicly in a de-identified format. Additionally, we created a regularly-updated [COVID-19 page](#) on our website to keep our community informed about pandemic issues related to PSC and other related conditions. Additionally, we offered three webinars focused on coping with PSC during the pandemic.

New, Enhanced Website

The PSC Partners website is a vital, dynamic, educational tool for the PSC community. In 2020, PSC Partners launched an improved version of the [website](#) for more effective and impactful dissemination of information.

The website serves as a hub for the PSC community, and provides continually-updated material for PSC patients, PSCers facing a transplant, caregivers, parents, and more.

"Our son was diagnosed with PSC... As our appetite for knowledge (about PSC) broadened, our search scope narrowed which brought us to PSC Partners. The first glimmer of hope in what seemed like an eternity of despair."



Additional Accomplishments

PSC Partners Patient and Caregiver Conferences

"If I didn't come to the conference, I would be heartbroken to have to wait another year to see everyone."

PSC Partners Seeking a Cure holds a [conference](#) every year, in conjunction with a major medical center. The conference draws patients and caregivers together (spouses, partners, parents, siblings, and friends of PSC patients) to learn about the latest research on treatments, medications,

procedures, and disease outlook. There are peer support and discussion sessions with physicians. Speakers at our conferences are internationally-recognized PSC thought leaders, and they come from the U.S. as well as international PSC treatment and research centers. The first conference was held in 2005. While the 2020 and 2021 conferences were postponed due to the COVID-19 pandemic, we are excited to gather, once again, in 2022 for the [16th PSC Partners Seeking a Cure Conference](#) in Boston, MA, in conjunction with Brigham and Women's Hospital and Massachusetts General Hospital.

International Research Forum

During the 2022 PSC Partners Conference, PSC Partners will conduct an International Research Forum bringing researchers together with our community to promote collaboration and expand research strategies for PSC.

PSC-Specific ICD-10-CM Code

PSC Partners obtained the first PSC-specific [ICD-10-CM code](#) (K83.01) that finally provides researchers with a robust tool for identifying PSC patients throughout the U.S., conducting epidemiological and natural history studies, and facilitating clinical trials. PSC Partners continues to promote awareness of this vitally important, disease-specific code.

Living with PSC Podcast and Monthly E-Newsletter



Thanks to the brilliant time and effort of PSC patient, volunteer, and Media Producer Niall McKay, PSC Partners has produced 21 episodes of our [Living with PSC Podcast](#). Each month, this podcast explores the latest research and knowledge about PSC. Topics range from patient stories to the latest research updates from PSC experts to collaborations that are crucial to finding better treatments and a cure for PSC. PSC Partners also distributes a monthly e-newsletter [The Duct](#), to ensure our PSC community stays up-to-date about advances towards a cure, events, support opportunities, fundraising activities, conference updates, and more.

The Future

PSC Partners Seeking a Cure remains dedicated to our mission of finding effective treatments and a cure for primary sclerosing cholangitis (PSC). We are also focused on supporting the thousands of PSC patients, families, and caregivers who are impacted by PSC. We constantly review, enhance, and expand our programs and initiatives to ensure they are impactful, effective, and inclusive.

Additionally, we continue to look for new programs and projects that move us closer to our vision of a world without primary sclerosing cholangitis (PSC). We remain together in the fight, whatever it takes.

"They provide so much valuable information and resources for people diagnosed with PSC. The conferences are exceptionally done and so beneficial. The Facebook page is a wonderful place for people to ask questions, get answers, and post in a safe place about this frustrating and awful disease."