

Together, we are
creating a world
where a PSC
diagnosis comes
with a cure!



Annual Report 2020



EDUCATION • COMMUNITY • RESEARCH

Our Mission:

The mission of PSC Partners Seeking a Cure is to drive research to identify treatments and a cure for primary sclerosing cholangitis (PSC), while providing education and support for those impacted by this rare disease.

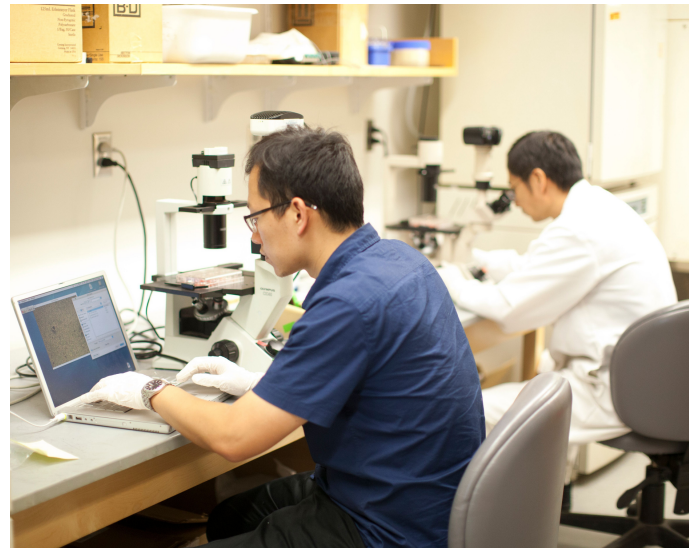


Primary Sclerosing Cholangitis (PSC) does not discriminate based on age, race, or gender, but affects more males than females.

- **Many PSC patients are asymptomatic at the time of diagnosis.**
- **It is estimated that there are close to 50,000 PSC patients in the United States, alone.**
- **One in every 10,000 people worldwide is diagnosed with PSC.**
- **PSC often is found in people with inflammatory bowel disease (IBD), most often ulcerative colitis (UC) and sometimes Crohn's disease.**
- **More than 75 percent of PSC patients have UC. PSC also is associated with other autoimmune diseases.**

PSC Partners Supports Research

Every year, on the recommendation of the Scientific/Medical Advisory Committee (SMAC) and a final vote of the board of directors, PSC Partners Seeking a Cure supports the most promising international PSC research. Grants are awarded to projects addressing an important and novel, basic, or clinical question related to PSC. For PSC Partners, this is a crucial endeavor bringing the PSC community closer to new treatments and an eventual cure. Through 2020, 97 grants have been awarded internationally for a total of \$4,093,666.



2020 Research Grants

YOON-YOUNG JANG

Human Disease Model of PSC for Discovery of Effective PSC Therapy

JOY XIAOSONG JIANG

Treating PSC with Idebenone

EVAGGELIA LIASKOU

Exploring the Metabolic Profile of T Cells in Patients with PSC (Canada)

XIAOYING LIU

The Role of Activating Transcription Factor 4 in PSC

ESPEN MELUM

Defining the Interactome of Bile Duct Inflammation in PSC

FANYIN MENG

The Beneficial Effects of Endothelial Progenitor Cells in PSC

ALAN C. MULLEN & DANIEL S. PRATT

Creation of Liver Organoids from Pluripotent Stem Cells Derived from Donors with Primary Sclerosing Cholangitis (PSC) (Canada)

JOEL PEKOW

Mucosal Markers to Predict the Onset of Colonic Neoplasia in Inflammatory Bowel Disease Patients with PSC (Canada)

PASQUALE PICCOLO

Micro-RNA Based Therapy for Primary Sclerosing Cholangitis

STEPHANIE ROESSLER & BENJAMIN GOEPPERT

Integrative Analysis of Intraductal Papillary Neoplasia of the Bile Duct in Patients with Primary Sclerosing Cholangitis

YU DU

2020 AASLD/PSCP One-Year Pilot Award

Studying Primary Sclerosing Cholangitis by Bioengineered in vitro Vascular Biliary Model

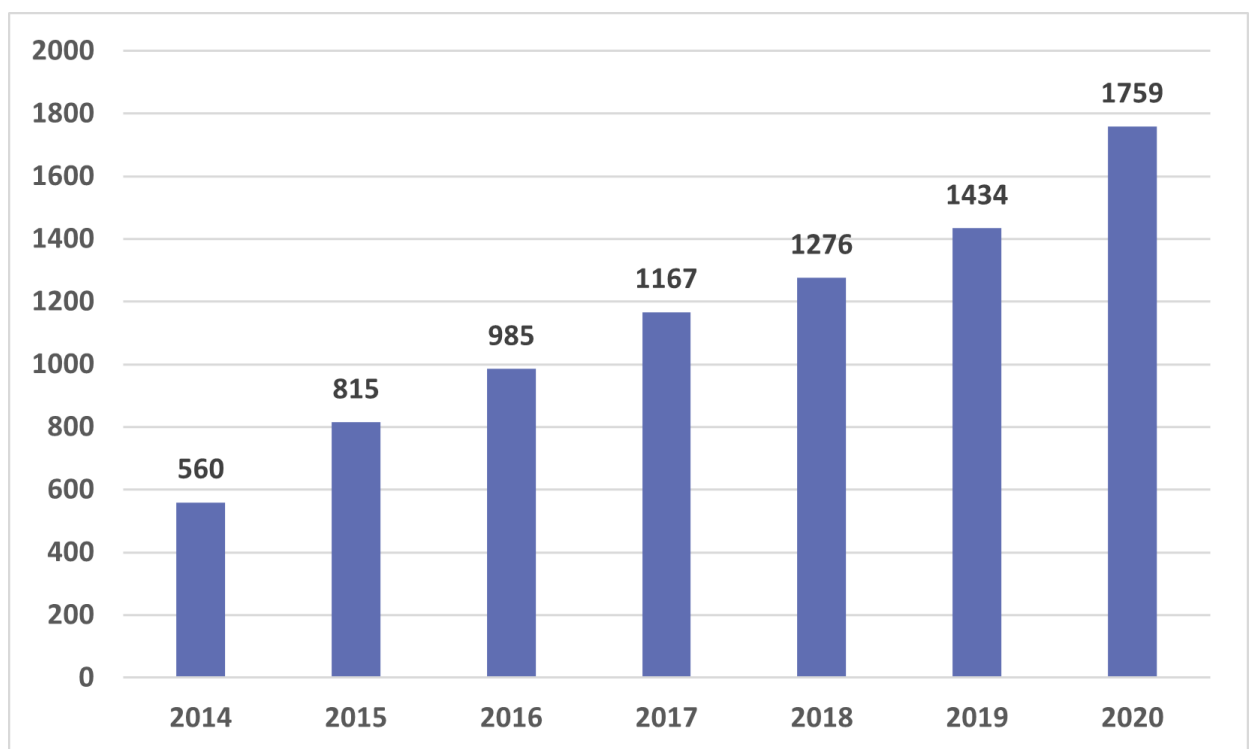
PSC Partners Registry

"I thought now was as good a time as any to fill out the registry, become a participant, and help the community fight PSC together."

-- PSC Patient

The aim of the PSC Partners Patient Registry is to collect basic data on PSC patients; increase and accelerate research; advocate for the unmet needs of PSC patients; recruit for clinical trials in search of PSC treatments; and facilitate studies leading to a better understanding of PSC. By providing disease-specific data to researchers via the growing PSC Patient Registry, supporting cutting-edge research, and more, there is hope that treatments will soon be discovered, greatly improving quality of life for PSC patients.

Participation in the PSC Partners Patient Registry has increased every year.



Education and Support

"My mother lives life to the fullest, and I'm sure she will continue to do so. Thanks so much for welcoming me. This is such an amazing group of people!"

-- PSC Caregiver

PSC Partners provides education and support for those impacted by PSC, including:

- our annual conference
- webinar series
- online support
- opportunities such as ZoomRooms
- dynamic website, which was revamped in 2020
- monthly newsletter
- Living with PSC podcast
- mentor program, and more.

Maintaining these outreach and support avenues is vital to the health and well-being of those in our PSC community.



2020 Board of Directors

*"Thank you to each and every one of you.
We will find those treatments and a cure."*

-- PSC Patient

PSC Partners is fortunate to have a talented and motivated group of volunteers serving on its board of directors. Members come from a variety of backgrounds and experiences and are united by a common cause to find a cure for PSC. All board members are either PSC patients or caregivers.

- Ricky Safer – CEO
- Fred Sabernick – Chair
- Joanne Grieme – Vice Chair
- Britt Moore – Secretary
- Jennifer Sims – Treasurer
- Rachel Gomel
- Stuart Barnett
- Nicole DeSantis
- Kathy Halloran
- Wes Hendrix
- Jesse Kirkpatrick
- Willie McKinney
- Matt McMurtry
- Leah Sciabarrasi
- Travis Stoltzfus



2020 Scientific/Medical Advisory Committee (SMAC)

The Scientific/Medical Advisory Committee (SMAC) shares their time and expertise to direct the path of the PSC Partners research program in order to find new treatments and a cure for PSC. All research grant proposals submitted to PSC Partners are reviewed annually by the SMAC.

- Dr. Christopher L. Bowlus - Co-Chair
- Dr. Richard Green - Co-Chair
- Dr. David Assis
- Dr. Annika Bergquist
- Dr. Dennis Black
- Dr. John Eaton
- Dr. Bertus Eksteen
- Dr. Heather Francis
- Dr. David Goldberg
- Dr. Denise M. Harnois
- Dr. Gideon Hirschfield
- Dr. Johannes R. Hov
- Dr. Josh Korzenik
- Dr. Cynthia Levy
- Dr. Cara Mack
- Dr. Stephen Miller
- Dr. Cyriel Ponsioen
- Dr. James Tabibian

Top Three 2020 Accomplishments

"I am at a loss for 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."

-- Virtual Attendee, PFDD Forum

Making Our Voices Heard: Patient Focused Drug-Development Forum

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.

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. The project 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.

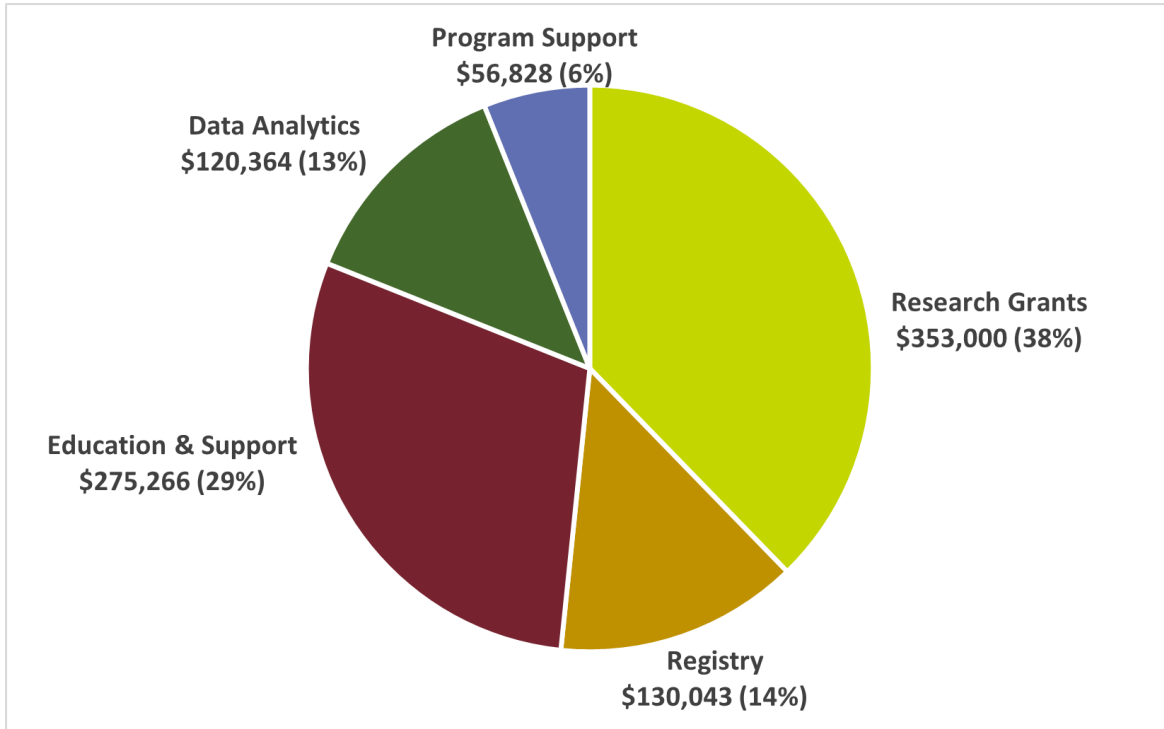
PSC Partners Conference Webinar Series

In 2020, we conducted seven informative webinars, in lieu of our postponed, in-person 2020 Conference, to ensure that our U.S. and global communities stayed informed and educated about PSC, treatments, PSC research, and more.

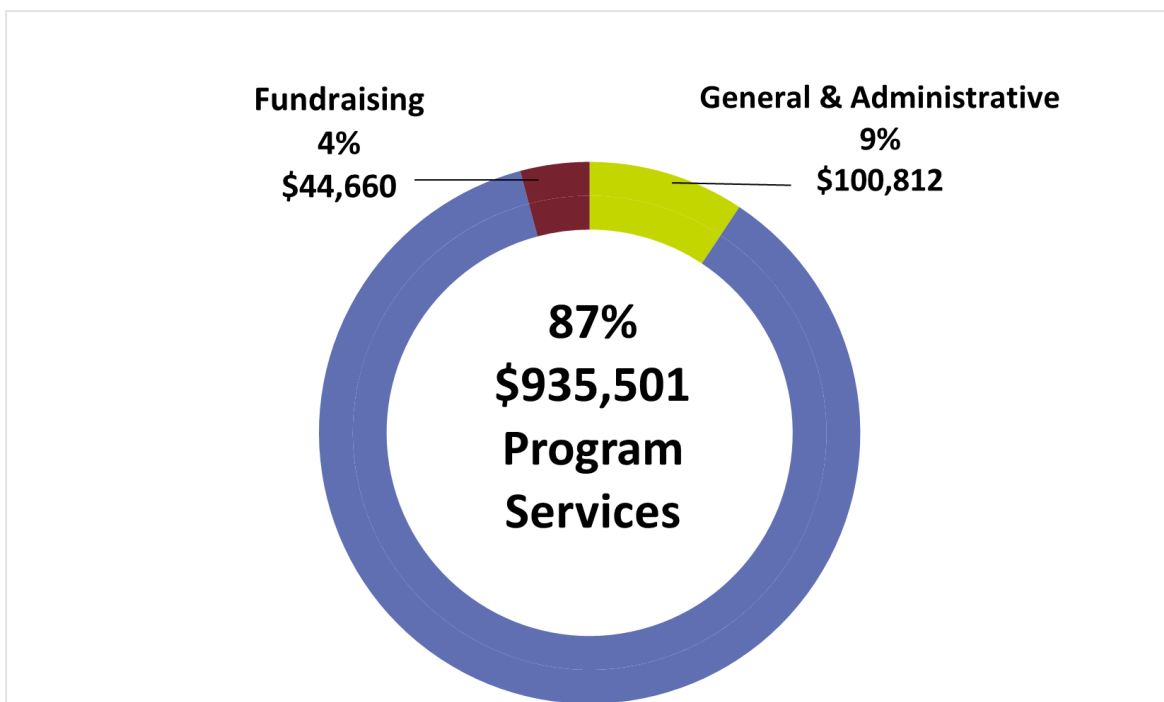
Financial Highlights

For the years ending Dec. 31, 2020 and 2019

Program Services



Annual Operating Expenses



Assets, Liabilities, and Net Assets

	2020	2019
ASSETS	\$2,718,056	\$2,151,795
LIABILITIES	\$64,750	\$3,606
NET ASSETS	\$2,653,306	\$2,148,189

Summary of Revenues & Expenses

	2020
CONTRIBUTIONS	\$1,321,290
CONFERENCE REVENUE	\$157,237
INVESTMENT REVENUE	\$94,589
OTHER REVENUE	\$12,974
TOTAL REVENUE	\$1,586,090
EXPENSES	\$1,080,973
CHANGE IN NET ASSETS	\$505,117



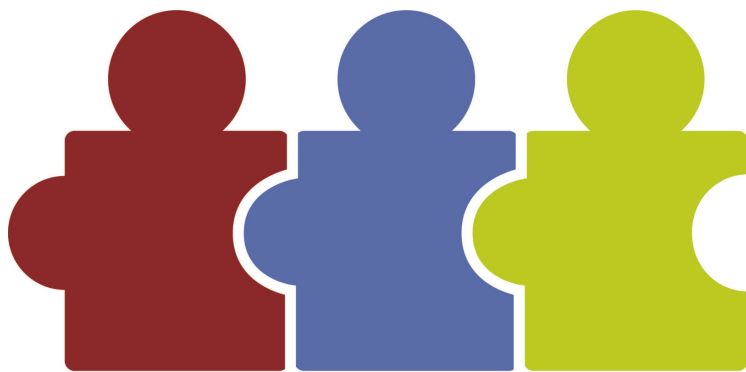
Questions or Concerns?

Email: ContactUs@PSCPartners.org

Call: 303-771-5227

Website: PSCPartners.org

Follow us on social media!



**PSC PARTNERS
SEEKING A CURE**

pscpartners.org

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This is a printable copy of the 2020 Annual Report.