



THE DUCT

A Monthly Newsletter for the PSC Community

December 2017

[Patient Registry](#) [2018 Conference](#) [Donate Now](#)

Wishing You and Your Family
Happy and Healthy Holidays!!



Education / Research / News



Listen Up: PSC Podcasts Are Here!

We are excited to announce that we will be sharing two new podcast series with you in the upcoming months. The podcasts focus on topics of interest to many in the PSC community. Monika Aldarondo, PSC patient (pictured above), is working on a series of podcasts entitled PSC Mami. Her podcasts will cover the intersection of PSC and parenthood and feature some fascinating interviews with people in our community who have grappled with the many issues surrounding PSC and

parenthood. Check out her recent [blog post](#) to learn more about Monika's motivation to start this blog, read her introduction to PSC Mami and listen to her first podcast. We hope you will find it as fascinating as we did and look forward to sharing her future podcasts with you.

We also want to introduce you to Niall McKay, a journalist and filmmaker who will be narrating a series of monthly podcasts featuring interviews with international PSC researchers on the latest research and conversations with patients and caregivers. Some upcoming topics are: what is PSC, coping with PSC, live vs. cadaveric transplantation, fecal transplants, genetics and PSC and many more. Stay tuned for more information about this new podcast series next month.



Two Turtle Doves and Another Patient in the Registry.

The end of the year is coming and there's just one week left to join our patient registry in 2017. We are looking for ONE more PSCer to help us

ring in the new year by joining our registry. In the hopes that we might entice you to join it, we revised the refrain in a popular holiday "diddy". Ready?

"Four calling birds, three french hens, two turtle doves and ANOTHER PATIENT IN THE REGISTRY!"

Sing it again.

"Four calling birds, three french hens, two turtle doves and ANOTHER PATIENT IN THE REGISTRY!"

Help us show the medical profession how passionate we are for better treatments and a cure and JOIN THE REGISTRY TODAY! [Register today!](#)

As always, we are deeply grateful to Rachel Gomel for her tireless work not only to get the registry up and running, but also to get PSCers registered. Thank you Rachel!!!



2017 PSC Partners Research Recap

Rachel Gomel provided a very nice recap of the research studies that were funded in 2017. If you haven't seen these summaries yet, please visit our [year- end accomplishments page](#). We are truly grateful for your generous support in making this research happen!

Community Spotlight



Caregivers: Arguably a PSC Patient's Most Important Resource! *By Mike Pearlman*

Caregivers are a critical part of the PSC Partners family. Caregivers offer comments, advice, and their own questions


through our [Open Facebook Support Group](#) and [Closed Facebook Support Group](#). In addition, the PSC Partners' website has "[Caregiver Information](#)". This document shares the experiences and views of many people, primarily those with PSC and their caregivers. While recognizing that caregiving is unique to each person (there is no one right way), it covers many of the areas that have direct impact on the person with PSC, his/her caregiver, and others (family, friends, etc.). Among the topics covered are the PSCer-Caregiver relationship; making time for yourself; dealing with medications; advocacy; planning; and dealing with the outside world. It is specifically focused on those impacted by PSC, and we believe you may find it helpful. In addition, because this is a "living" document, we invite you to share with us (contactus@pscpartners.org) your thoughts and suggestions on its content.



**ATTENTION CALIFORNIA
AREA PSCers - Save the date:
PSC / PBC Patient Meeting on
January 27th, 2018 at UC**

Davis Medical Center

Attention California and surrounding area PSC and PBC patients: UC Davis Medical Health Center is hosting a patient meeting.



UC DAVIS
HEALTH

PBC / PSC PATIENT MEETING
JANUARY 27, 2018
9:00 AM - 12:00 PM

Purpose:
Learn more about PSC / PBC including:

- Update on clinical trials and possible new therapies
- Potential causes of PSC / PBC

GENOME AND BIOMEDICAL SCIENCES FACILITY (GBSF)
AUDITORIUM (1ST FLOOR)
UNIVERSITY OF CALIFORNIA DAVIS
451 E. SCIENCES DRIVE
DAVIS, CA 95616

FOR MORE INFORMATION CONTACT:
CHUNG HENG (PETER) LIU CHLIU@UCDAVIS.EDU (916) 734-8985
SANDEEP DHALIWAL SANDHALIWAL@UCDAVIS.EDU (916) 734-8696

UC Davis is also looking for healthy controls for a research study. Below are the criteria:

Eligibility: We are looking for healthy women 50 to 65 years old that have no history of liver disease and that are not currently taking immunosuppressive medication.

Subjects will sign a consent form, complete a brief questionnaire and provide a FASTING blood sample.

Compensation: \$20 prepaid Target card

New Post from Nutritionist and Guest Blogger Brittany: How to Eat When You're Exhausted Part 2



We recently announced two new guest bloggers who will be sharing their stories and insights about nutrition and other topics with our community. Visit [our blog](#) to see the latest post by [Brittany](#) on PSC and nutrition!

If you have something you'd like to share with our community, feel free to contact us at contactus@pscpartners.org to share your ideas for what you'd like to read or write about on our blog.

How You Can Support Us



Support PSC Partners with a Donor Advised Fund (DAF)



The screenshot shows the DAF DIRECT donation form. At the top is the DAF DIRECT logo. Below it is a link that says "What is this?". The form has three main sections: "Donate now from:" with a dropdown menu showing "-- Please select --"; "Designation:" with a text input field; and "Amount:" with a text input field containing a dollar sign (\$) and a blue "NEXT" button.

A donor advised fund (DAF) is a type of giving program administered by a third party that provides you with the flexibility and most favorable tax benefits to easily support your favorite charities. DAFs are designed to manage charitable donations on behalf of an organization, family or individual and are becoming increasingly popular. They are an excellent way to simplify your charitable giving and facilitate your strategic philanthropic goals.

You will receive a tax deduction when you make a contribution of cash, stock and other assets and, at a later time, you can grant specified amounts to the charities of your choice. Read our recent [blog post](#) to learn more about the benefits and how they work.

Organizational News

SAVE THE DATE FOR PSC PARTNERS 2018 ANNUAL CONFERENCE

June 22nd-24th, 2018, in collaboration with **UC Davis Medical Center**, Sheraton Grand Hotel, Sacramento, CA. More details to come.



Local Support Groups

Interested in starting or joining a local PSC Support Group? To learn more on this, please visit pscpartners.org/support-groups and/or [e-mail PSC Partners](mailto:pscpartners@pscpartners.org).

*Note: local support groups are not endorsed by PSC Partners and are fully independent of PSC Partners. PSC Partners accepts no responsibility for any information, activities, or costs associated with local support groups.

The mission of PSC Partners 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

