



# THE DUCT

A Monthly Newsletter for the PSC Community

February 2019

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*"We learned so much and met such wonderful people. Before this we had never met another person or family dealing with PSC. Now we don't feel so alone and isolated. In fact, we feel encouraged and supported." - PSC Partners Conference Attendee*

As a Valentine's Day treat, give yourself a gift by planning to attend the upcoming PSC Partners patient and caregiver conference, June 21-23, 2019.

[Click here](#) for 2019 Conference information.

## Community Members Needed Sponsor the PSC Partners Conference June 21-23, 2019



Did you know that conference sponsorship is not just for corporations? Individuals, couples, and families can help out too, because, while engaging

the PSC community is a labor of love, it also is lots of work. Achieving our mission takes a village of committed volunteers, community members, and donors.

Your investment in PSC Partners' 2019 Conference:

- Helps achieve our mission for the PSC community
- Enables us to make the event accessible to as many people as possible by subsidizing a significant portion of registration fees for all patients and caregivers

From providing a dinner to funding the audio visual equipment to making sure everyone has enough snacks, there are numerous sponsorship opportunities and levels available. Check them out [here](#).

Check out Corporate Sponsorship opportunities [here](#).

Click [here](#) for more information about the annual conference in Rochester, MN. Hotel rooms are filling up quickly. Don't delay.



## ***Living with PSC Episode 9 Dr. Konstantinos Lazaridis: Genetics & Environmental Exposures in PSC***

In the ninth episode of Living with PSC, Niall McKay

discusses the interaction between genetics and environmental exposures in PSC, with Dr. Konstantinos Lazaridis from Mayo Clinic Rochester. Listen to the discussion [here](#).

Dr. Lazaridis has received multiple PSC Partners research grants, and will be presenting at the 2019 PSC Partners Conference.

The Living With PSC podcast series is moderated by 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 list of past episodes.

# Deadline for Grant Applications: March 23, 2019

Applications are now being accepted for PSC research grants. PSC Partners Seeking a Cure and affiliate PSC Partners Canada offer these grants to researchers conducting scientific investigations addressing an important and novel, basic, or clinical research question related to primary sclerosing cholangitis (PSC) and closely associated diseases, such as inflammatory bowel diseases (IBD) and cholangiocarcinoma.

Click [here](#) for more information and to apply for a grant.



## **Feb. 28, 2019** **Show Your Stripes** **on** **Rare Disease Day**

Feb. 28th is National Rare Disease Day. The National Organization of Rare Diseases (NORD) is encouraging the

PSC community to wear stripes to show solidarity with others impacted by rare diseases. Why stripes? The zebra is the official symbol of rare diseases in the U.S. and is noted for its black and white stripes, which are central to its uniqueness. Everyone has his/her own stripes, those characteristics that make each individual distinct. While each of the more than 7,000 rare diseases is unique, there are many commonalities that unite the rare disease community.

The main objective of Rare Disease Day is to raise awareness amongst the general public and decision-makers about these diseases, including PSC, and their impact on patients' lives.

You can help! Snap and share photos/videos on social media of you, your friends, and your family wearing stripes. Use the hashtags #PSCPartners, #showyourstripes, and #rarediseaseday.

Tag PSC Partners and NORD in your social media posts:

**Facebook:** @PSCPartnersSeekingACure @rarediseases

**Twitter:** @PSCPartners @RareDiseases

**Instagram:** @psc.partners @rarediseasedayus

You don't look good in stripes? No problem. Wearing your PSC Partners swag works, as well. If you'd like some new threads for the day, visit the PSC Partners online [shop](#).

PSC Partners and Rare Disease Day were featured in the Denver Post. Read the article [here](#).



## ***Government Employees... There's Still Time to Donate***



Due to the recent government shutdown, the deadline for federal employees to donate through the Combined Federal Campaign (CFC) has been extended. The online pledge portal will remain open until Friday, Feb. 22, 2019, at midnight. Click [here](#) to donate. The PSC Partners CFC code is 79370.

*If you've already donated, thank you!*

## ***As Heard @ 2018 Conference Practical Approaches to Relieving PSC Symptoms***



At the 2018 PSC Partners Conference, Dr. Marion Peters discussed practical approaches to managing symptoms in PSC, including itching, fatigue, and more. View her entire presentation [here](#).

Check out information and presentations from past conferences [here](#).

# Cars For A Cure!



Magically turn your ol' jalopy into a vehicle for a cure. Well, actually, it's not magic, and you don't have to be a wizard to do it. The donation of a car, in any condition, can be turned into funds to help PSC Partners Seeking a Cure.

Click [here](#) to get the process rolling!

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*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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