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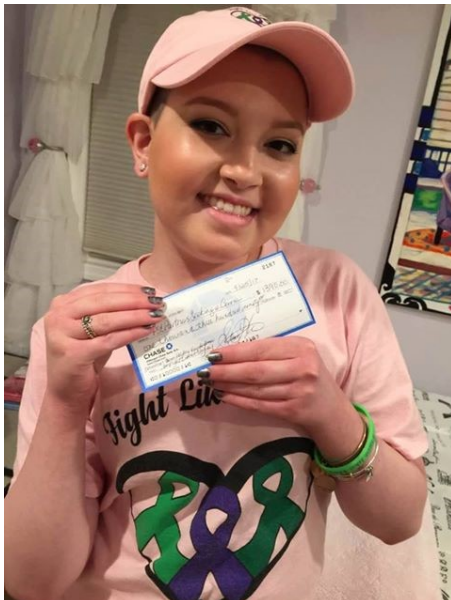
A Monthly Newsletter for the PSC Community

November 2017

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

*We are always looking for interesting people, research and stories to feature in our newsletter. Please [contact us](#) if you'd like to see your story or research featured in a future issue or if you are interested in being a guest-blogger for us. Don't be shy!*

HAPPY THANKSGIVING!!!!  
WE ARE THANKFUL FOR YOU!



**A Heartfelt Thank You to the Many People Who Have Donated, Created Personal Fundraisers and Volunteered their Time and Talent!**

Thank you to all who have taken the time to fundraise and donate to PSC Partners this year! Your contributions empower us to continue the important work we are doing and, together, we are making amazing progress! This year, we have seen a huge

increase in interest in finding better treatments for PSC from researchers, pharmaceutical companies and regulators which gives us reason to be optimistic that better treatments and a cure are on the horizon.

As Thanksgiving approaches, we want you to know how thankful we are for your generosity and commitment to a better future for those suffering with PSC. Pictured above is one example of the extraordinary strength and generosity that radiates from our community. You will learn more about this incredible young lady soon! Stay tuned.

## Education / Research / News



### **PSC Partners Welcomes David Assis, MD and John Eaton, MD to our SMAC Committee**

We are excited to announce that we have selected two new members to support us via our [Scientific / Medical](#)

[Advisory Committee](#). SMAC Committee members share their time and expertise with us to direct the path of our research program and ensure the scientific merit of the grants we award. Dr. Assis and Dr. Eaton bring a wealth of experience and expertise in working with PSC patients and we are most excited to benefit from their direction.

Following are brief bios about each of them:

Dr. Assis completed his medical school and residency training at Jefferson Medical College in Philadelphia, PA, where he was also a chief resident. He moved to New Haven, CT, to pursue clinical and research expertise in hepatology during his fellowship at Yale University. Dr. Assis also completed a transplant hepatology fellowship. He is now an Assistant Professor of Medicine at Yale, where his clinical and research interests focus on autoimmune liver diseases, including Primary Sclerosing Cholangitis and Autoimmune Hepatitis.

Dr. John Eaton is an Assistant Professor of Medicine and Transplant Hepatologist at Mayo Clinic in Rochester, Minnesota. Dr. Eaton completed his internal medicine residency training, Chief Medical residency, Gastroenterology & Hepatology fellowship and an advanced Liver Transplant fellowship at Mayo Clinic in Rochester, Minnesota. Dr. Eaton also designed and completed a unique 1 year training program that enabled him to focus on cholestatic liver diseases and cholangiocarcinoma prior to joining the staff at Mayo Clinic in Rochester, Minnesota. Dr. Eaton's clinical efforts are focused on seeing patients with PSC, PBC and cholangiocarcinoma. His research focuses on clinical trials, advanced imaging studies and improving our understanding of the natural history of PSC and methods to predict key outcomes.



We are also excited to have [Dr. James Tabibian](#) rejoin SMAC after a short leave of absence. Dr. Tabibian will act as the SMAC liaison to the Board of Directors.



### **Interested in Learning More About the 2017 Research Grant Awardees?**

Visit our [research page](#) to read the lay summaries for our most recent grant awardees.

If you prefer to get your information in tidbits, research updates will also be posted on our blog every couple of weeks. Below is our latest research summary. This study was funded by PSC Partners Canada and we were delighted to bump into Dr. Popov (pictured above) at the recent AASLD meeting.

### **[Integrin AVB6 as a Therapeutic Target for Primary Sclerosing Cholangitis - Associated Cholangiocarcinoma.](#)**

**Principal Investigators**

- **Yury V. Popov, MD, PhD**, Director, Liver Fibrosis Research, Assistant Professor of Medicine, Division of Gastroenterology and Hepatology, Beth Israel Deaconess Medical Center, Harvard Medical School, Boston, MA

Thank you Dr. Popov for choosing to research therapeutic targets for PSC. We can't wait to see where your study takes us!

## Community Spotlight

### **In Memory of PSC Partners Former Board Member and SMAC Advisory Committee Member, Dr. Aubrey Goldstein**



PSC Partners Seeking a Cure has lost a beloved member of its family. As a primary sclerosing cholangitis patient, and later, as a transplant recipient, Aubrey, and equally his wife Caroline, have been integral to our organization.

During PSC Partners' 14 years of existence, Aubrey has been a constant and glowing presence. He is what we call in the PSC Partners community, a "lifer," a steadfast and dedicated member of our close-knit PSC family who has attended all of our past conferences. Aubrey and Caroline never missed our annual conferences, lovingly called "family reunions." They knew how to add as much knowledge as lightness and laughter to PSC, a condition that otherwise is associated with anxiety and uncertainty.

Aubrey was equally committed to our search for treatments and a cure for PSC. For years, he served as volunteer both on the PSC Partners Board of Directors and on its Scientific / Medical Advisory Committee. He tirelessly advocated for organ donation awareness and he and Caroline lived what they believed in, selflessly and fully.

A year ago, with the launch of the Canadian affiliate of PSC Partners Seeking a Cure, Aubrey and Caroline appeared at the home of Mary Vyas, the new affiliate's president, to personally deliver the very first donation to PSC Partners

Canada. Their enthusiasm and commitment know no boundary.

We may have lost a fearless PSC warrior, but his spirit will continue to shine in our tiny mighty army, and always, through Caroline.

## November is National Family Caregivers Month (NFC)

*By Mike Pearlman*

November is National Family Caregivers

Month! The first NFC Month Presidential Proclamation was issued in 1997, and has continued each year. The National Family Caregiver's Month is intended to raise awareness of family caregiver issues and to increase support for, and to honor, family caregivers. The theme this year is "Caregiving Around the Clock". You can learn more and find [additional resources](#) designed to support caregivers [here](#).

10 Tips for Family Caregivers



## How You Can Support Us

### Annual Campaign Season is Upon Us!

PSC Partners couldn't exist without the support of our community. We are all equally committed to our mission of finding better treatments and a cure for our loved ones who suffer with PSC. In the upcoming months, we will be sharing information and requesting your support. We've come a long way in this past year and are excited about the future. Maintaining our momentum is more important than ever because we have the support of the most vital stakeholders - clinicians, researchers, pharmaceutical companies and regulators. With your support, we can continue to push our mission of finding better treatments and a cure forward. We hope that you will consider supporting PSC Partners as part of your holiday giving this year! Stay tuned for an email from



Ricky Safer to learn more about our 2017 accomplishments and how you can support us.

## #GIVING TUESDAY

### Mark Your Calendar: **GIVING TUESDAY IS November 28th!!!**

Giving Tuesday is a global giving movement that has been built by individuals, families, organizations, businesses and communities in all 50 states and in countries around the world. Giving Tuesday is a celebration of America's greatest traditions: generosity, entrepreneurship and community. Everyone has something to give. You can give time or expertise, monetary donations large or small, simple acts of kindness, food or clothing.

This year, #GivingTuesday falls on November 28<sup>th</sup>. It inspires people to take collective action to improve their communities, give back in better, smarter ways to the charities and causes they believe in and help create a better world.

#GivingTuesday demonstrates how every act of generosity counts, and that they mean even more when we give together.

Get a jump on the day and donate to PSC Partners today!

**DONATE TO  
PSC PARTNERS TODAY!**



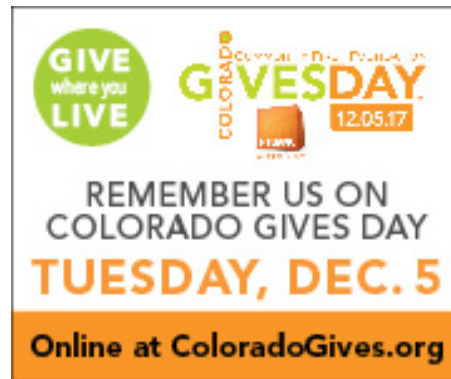
### Support us when you Shop on Amazon Smile This Holiday Season

Shop for everyone on  
your gift list this

holiday at [smile.amazon.com/ch/20-2112635](https://smile.amazon.com/ch/20-2112635) and Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to PSC Partners Seeking a Cure. Amazon Smile is a simple way to give to a most important cause!

## Attention Coloradans: Support PSC Partners on Colorado Gives Day!

Colorado's largest day of giving, Colorado Gives Day, is taking place on Tuesday, December 5th, 2017. On this day, thousands of people come together to support Colorado nonprofits like ours. When you donate to PSC Partners, you're helping us educate and support patients and caregivers, build our patient registry and motivate and fund the research that is so critical for better treatments and a cure.



Please support PSC Partners on December 5th. Thanks to the \$1M incentive fund from Community First Foundation and FirstBank, your donation goes further on Colorado Gives Day.

To donate to us on Colorado Gives Day, go to [PSC Partners Overview](#) on the Colorado Gives Website. You can schedule your donation any time after November 1st.

To learn more about Colorado Gives Day click [here](#).

*Colorado Gives Day is an annual statewide movement to celebrate and increase philanthropy in Colorado through online giving. Presented by Community First Foundation and FirstBank, Colorado Gives Day is powered by ColoradoGives.org*

## Tis the Season for Workplace Giving and the Combined Federal Campaign (CFC)



How can designating PSC Partners for your workplace giving make a difference? We just funded six new, PSC-focused research grants. With your help, there's more to come!

Check with your HR department to see if your organization has a workplace giving program and designate PSC Partners Seeking a Cure as recipient of your workplace giving campaign. Make the following designations, depending on

the campaign offered in your company:

[United Way](#) or other campaigns: Write in "PSC Partners Seeking a Cure" and our address: 6900 E. Belleview Ave. Suite 202, Greenwood Village, CO 80111.

### [Combined Federal Campaign](#) #79370

Are you a federal employee who wants to join PSC Partners in fighting this terrible disease? CFC is the world's largest and most successful annual workplace charity campaign, with almost 200 CFC campaigns throughout the country and overseas raising millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season (October 2nd to January 12th) support eligible non-profit organizations that provide health and human service benefits throughout the world. <https://www.opm.gov/combined-federal-campaign/>

**\*\*Please note that we can only acknowledge your donation if your employer shares your name with us. We encourage you to select PSC Partners Seeking a Cure as your charity of choice! As 2017 begins to draw to a close, please remember PSC Partners during your workplace giving campaign. Together, we will continue to make strides towards better treatments and a cure for PSC.**



### **Support PSC Partners with a Donor Advised Fund (DAF)**



A donor advised fund (DAF) provides you with the flexibility and most favorable tax benefits to support your favorite charities. DAFs 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. Read our recent [blog post](#) to learn more about the benefits and how they work.

## **Organizational News**



## **AASLD Conference Highlights**

In October, for the 6th year in a row, PSC Partners attended the AASLD (American Association for the Study of Liver Diseases) Liver Meeting. This year's Liver Meeting, attracted 10,500 hepatologists from around the world and provided a forum to discuss the most recent developments in the study and treatment of liver diseases.



The value of meeting face-to-face with the world's top hepatologists, physicians, researchers, and industry representatives to discuss our current activities and research projects cannot be understated. Some of our most productive collaborations began through contact at The Liver Meeting, and we value the opportunity to continue to foster these relationships and forge new ones. This year, we noticed that there is much greater awareness of PSC and a heightened interest in PSC among members of this community. Many researchers stopped by our booth to talk to our PSC Partners representatives, including people who have received grants, those who are thinking of applying for grants, and many hepatology leaders. We were excited to see that close to 400 medical professionals attended a session focused on providing stakeholders with updates on PSC!

Also of note, the PSC Forum (pictured above) capitalized on the opportunity to host a meeting the day before the conference to leverage the presence of international stakeholders. It was exciting to hear the discussions from the variety of stakeholders present (researchers, regulatory agencies and patient advocacy groups) and we remain excited about the promise the PSC Forum holds for PSC patients and their families.

## **NORD Conference Highlights**

In October PSC Partners attended the NORD (National Organization for Rare



Disorders) 2017 Summit. NORD is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD has over 260 patient organizations as members and is committed to the identification, treatment and cure for rare disorders through programs of education, advocacy, research and patient

services. The Summit provided us with valuable opportunities to network with other leaders from rare disease organizations and the FDA and to learn new strategies that will help us overcome some of the hurdles rare disease patients face. Below are a few important outcomes:

- Katie Randall was selected to serve as the Colorado Ambassador for the Rare Action Network. Powered by NORD, the Rare Action Network seeks to connect and empower the rare disease community through advocacy efforts at both the state and national level. Many of the challenges faced by PSC patients and caregivers are also problematic for other rare disease patients; by providing a united front, the rare disease community has a much more powerful voice to ensure that patients' unmet needs are addressed. To learn more about the Rare Action Network and to get involved, please click [here](#).
- PSC Partners seized on the opportunity to present a case for PSC patients to receive much needed disability benefits to the Social Security Administration. Trish Stoltzfus presented our cause in DC as a first step in the process. Thank you, Trish. More to come.
- We learned many new ideas that will benefit our patients. For example, one organization representing a poorly understood disease created a wallet-sized card that patients could bring to the ER with them to help ensure that they were treated properly. We thought something like this might be a useful resource for our patients to have handy when they go to the ER for a bacterial cholangitis infection. PSCSupport in the UK created a [leaflet](#) for this purpose and we thought a wallet-sized version of this might be helpful for our patients and caregivers.

## Pediatric PSC: NASPGHAN Highlights

In early November, PSC Partners exhibited at NASPGHAN (the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition) to share information about our research grants and desire to fund pediatric studies. Additionally, we were there to ensure that as many pediatric professionals as possible are aware of how PSC Partners can support their patients and caregivers.



A highlight of the conference was the incredible openness and interest from the pediatric medical professionals we had the pleasure of speaking with. We connected with over 80 new physicians and clinicians who weren't aware of us. Many thanked us for stopping them and were excited to hear that there was an organization like ours to refer their patients to for support. Others were excited to hear about the research grant opportunities we provide.

The following sessions were dedicated to PSC and/or related to promising research for PSC patients.

- Friday plenary session - Symptoms underestimate endoscopic activity in PSC-IBD.
- Organoids - Current and future promise for changing treatment of GI and liver problems.
- Improvement of GGT predicts event-free survival in PSC regardless of ursodeoxycholic acid treatment: data from the pediatric PSC consortium.
- Validating the Mayo Model of PSC outcomes in children: data from the pediatric consortium.
- Saturday Poster Session on pediatric PSC.

We are excited about the new connections we made and their potential to further research on pediatric PSC and expand our ability to support more PSC patients and their caregivers.

## 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](http://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.*

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