PSC PARTNERS
SEEKING A CURE

# THE DUCT

A Monthly Newsletter for the PSC Community

August 2018

Patient Registry 2019 Conference Donate Now

# 2018 Annual Conference: A Weekend of Hope, Education and Optimism

After a year of preparation, it felt like our fourteenth annual conference on June 22-24 passed by too quickly! It is hard to explain the magical positive energy that was generated when our community of 286 patients and caregivers arrived in Sacramento to learn about PSC and current research, to share our experiences and to celebrate the progress that we have made to find new therapies and an eventual cure for PSC. Attendees came from throughout the U.S. and Canada as well as from Australia, Israel, the UK and Iceland.

Dr. Chris Bowlus, our co-host from the University of California Davis, chose a variety of phenomenal speakers from UC Davis, California Pacific Medical Center, University of San Francisco, Stanford, UCLA, and Berkeley. The breakout and general sessions covered all aspects of PSC: medical, emotional, financial and everyday living. Attendees learned so much and had many opportunities to ask individual questions.

**If you weren't able to join us at the conference, please go to our 2018 conference web page, where we have posted PowerPoint slides for each breakout session as well as videos of all the general sessions.**

Thank you to our generous conference sponsors and all our conference volunteers, without whom the conference would not have been such a success. I am always touched by the compassion, openness and welcoming spirit of our community. You're the ones who shape our shared weekend experience. For me, it is always touching to watch the newcomers who arrive Thursday evening feeling isolated and worried, but who leave on Sunday afternoon armed with education, caring friends and knowledge that our PSC family is dedicated to working together to solve the mystery of PSC. Ken Hollander, a first time attendee, summed it up best: "I see the desperation of us all turn to hope and optimism. You allow us to go there."

Please save the dates of June 21-23, 2019 to join us at our fifteenth annual conference at the Mayo Clinic in Rochester, MN.

Sincerely,
Ricky Safer
CEO, PSC Partners Seeking a Cure

---

## Dr. Johannes Hov Receives €1.5 Million PSC Research Grant

Dr. Johannes Hov, a PSC researcher and member of PSC Partners' Scientific/Medical Advisory Committee, has been awarded an ERC Starting Grant from the EU in the amount of 1.5 Million Euros to support his research into the importance of intestinal bacteria in PSC and other chronic inflammatory diseases. To read more about the award, click here. We look forward to seeing the results of this incredibly promising research. Congratulations, Dr. Hov!

## Patient Registry Update: July 2018

*By Rachel Gomel, Registry Coordinator*

With 1220 participants that have shown their eagerness and enthusiasm for facilitating PSC research, the registry has already taken us a long way. The registry is growing in importance as more and more researchers are studying PSC for new treatments and for investigating factors that might be triggers for PSC. Through the registry, you have told us what matters most to you as PSC patients, and we have brought your messages to the FDA, academic researchers, and to industry. We have recruited registry participants for clinical trials and have cut down on the time it takes for researchers to obtain answers. Publications have resulted from your de-identified data. Thanks go to our dedicated registry participants who are committed to participating in studies and to finding treatments and a cure.

**We have one gap to fill. There is a shortage of men in the registry.** Though the ratio of men to women is 2 to 1 in PSC, in our registry, our disease looks like a female-dominated disease! We asked, and you responded: Following the conference, most of the new participants have been men!

As patients and families of patients, there is nothing we want more than treatments and a cure for PSC. We have expressed our resolve by awarding over $3 million in research grants and by the simple but important act of joining the registry. If you haven't joined the registry yet, this is the time to make our voices louder and clearer. If you have joined, we thank you from the bottom of our hearts for your ongoing participation. Take an active role and participate in the search for a cure. We're together in this fight, whatever it takes!

www.pscpartnersregistry.org

## Living with PSC Podcast Episode 4: A Conversation with Dr. Gideon Hirschfield

PSC Partners Seeking a Cure is pleased to present Living With PSC, a podcast moderated by Niall McKay. In the fourth episode of Living with PSC, Niall interviews Dr. Gideon Hirschfield about a variety of topics related to PSC. Dr. Hirschfield is a member of PSC Partners' Scientific/Medical Advisory Committee. Click here to listen!

## Summer Tips for IBD Patients

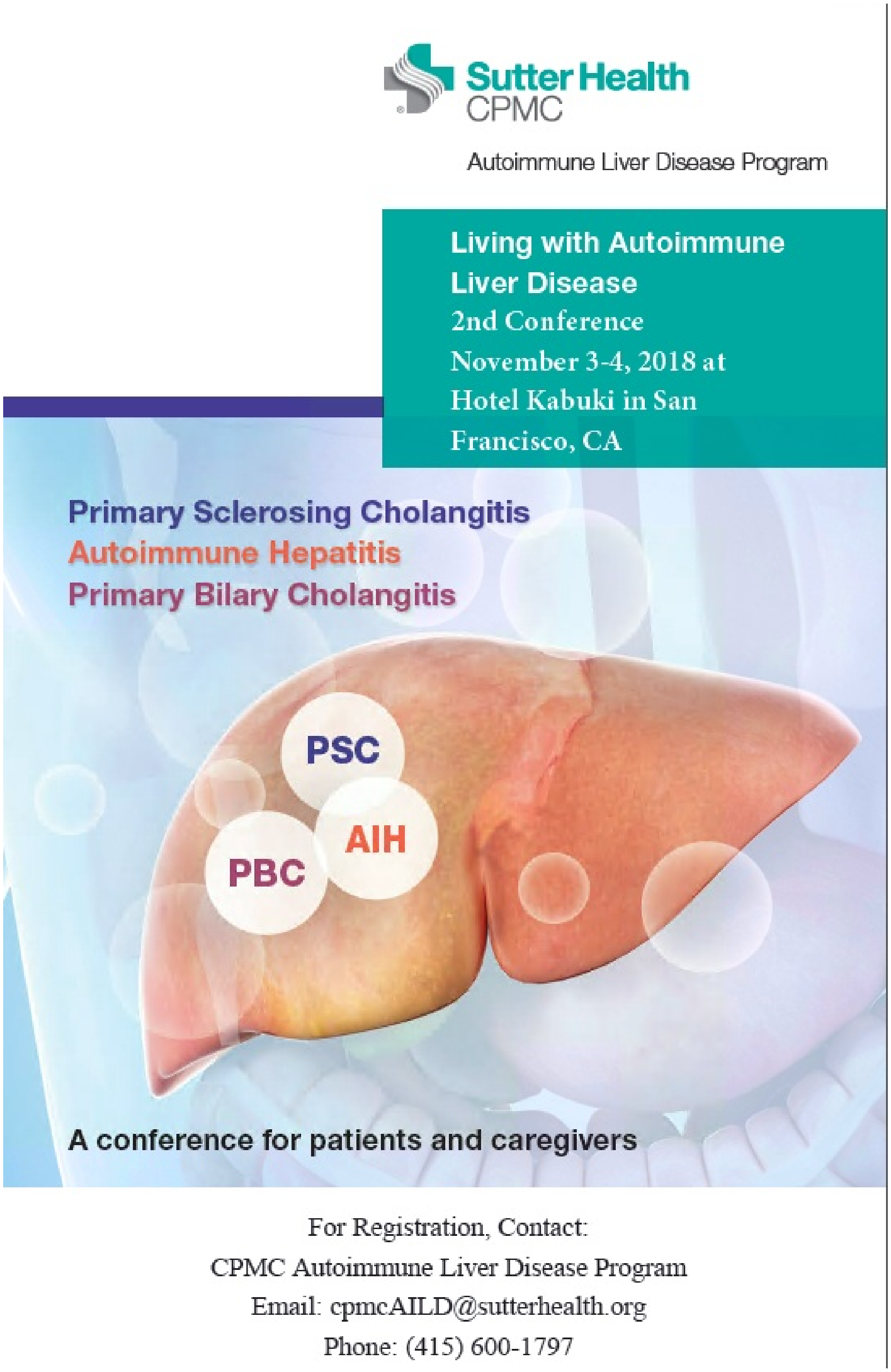
The Crohn's and Colitis Foundation has shared two helpful articles for IBD patients navigating the summer months: Sun Safety and IBD, and On the Road Again: Travel Tips for Summer Vacations. We wish everyone a happy and healthy August!

## Transitioning to Adult Care: A PSC Patient's Perspective

It can be a difficult process to transition from pediatric to adult care, particularly with a condition as complicated as PSC. Depending on the patient and their medical team, the transition can look very different from one PSC patient to the next. A PSC patient who recently completed the transition to adult care shares her thoughts about the process here.

# Upcoming Conference in San Francisco: Living with Autoimmune Liver Disease

On November 3-4, 2018 the California Pacific Medical Center (CPMC) Autoimmune Liver Disease Program will be hosting a conference for patients and caregivers living with autoimmune liver disease. Click here to view the Save the Date for this noteworthy event.



Sutter Health
CPMC

Autoimmune Liver Disease Program

**Living with Autoimmune Liver Disease**
2nd Conference
November 3-4, 2018 at Hotel Kabuki in San Francisco, CA

**Primary Sclerosing Cholangitis**
**Autoimmune Hepatitis**
**Primary Bilary Cholangitis**

**A conference for patients and caregivers**

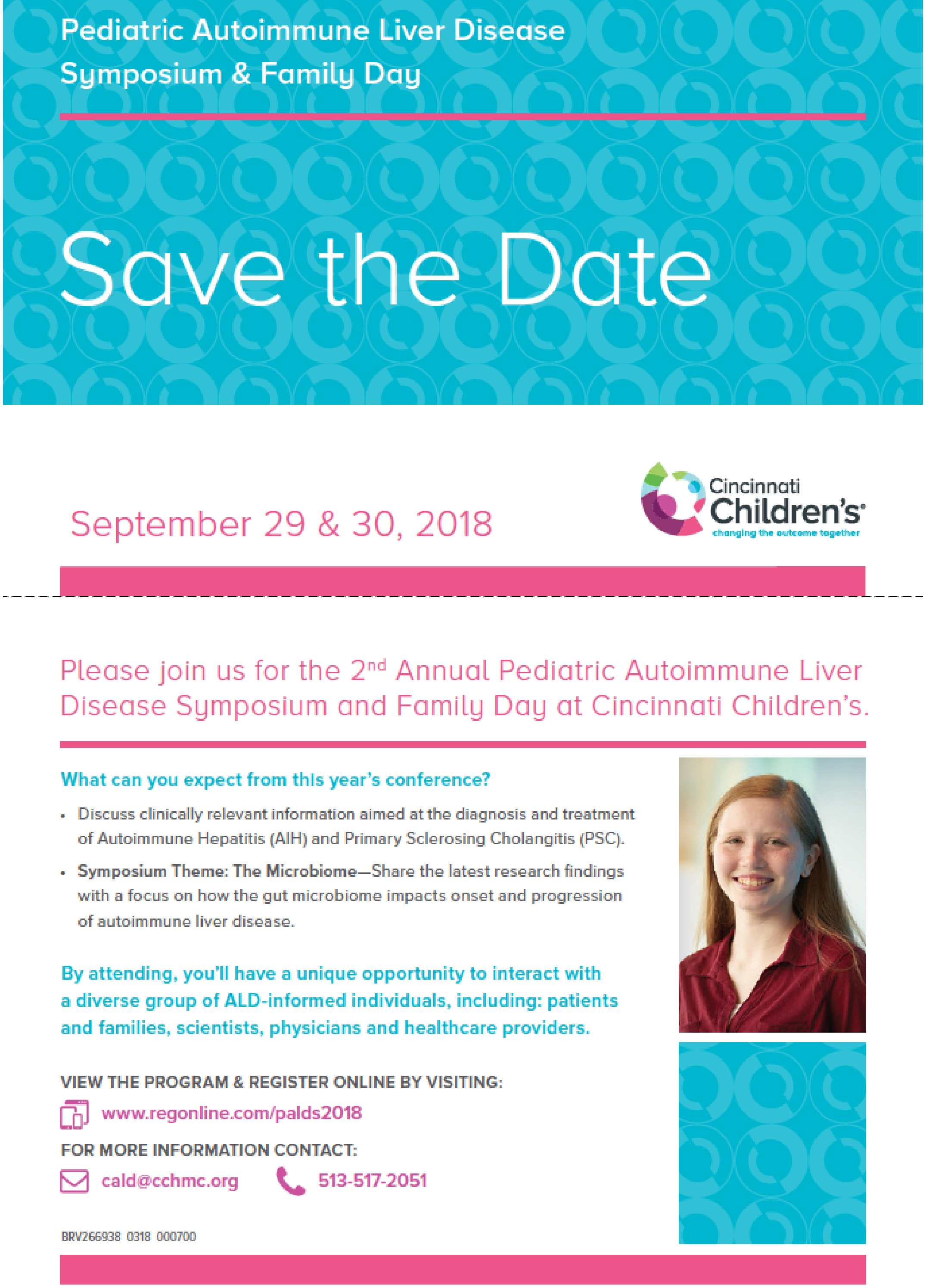
For Registration, Contact:
CPMC Autoimmune Liver Disease Program
Email: cpmcAILD@sutterhealth.org
Phone: (415) 600-1797

The CPMC Autoimmune Liver Disease Program also sponsors free monthly support meetings with a dial-in option for those who wish to attend remotely.

Those living with PSC, PBC, and Autoimmune Hepatitis (AIH), family members, loved ones, and caregivers are invited to participate in this group to learn and to share experiences with others. The purpose is to provide informational, emotional and other forms of support in an open, accepting environment. Educational sessions will be provided based upon topics of interest from the group.To register, email cpmcAILD@sutterhealth.org.

## Pediatric Autoimmune Liver Disease Symposium and Family Day
## September 29-30, 2018 in Cincinnati

The Center for Autoimmune Liver Disease (CALD) is hosting its second Pediatric Autoimmune Liver Disease Symposium & Family Day on September 29-30 at Cincinnati Children's Hospital and Medical Center. The symposium will feature information about research, treatment, and prediction of pediatric onset AIH and PSC, with a particular focus on the interplay between the gut microbiome and autoimmune liver disease. Click here for more information about the event and to register.



Pediatric Autoimmune Liver Disease Symposium & Family Day

# Save the Date

September 29 & 30, 2018

Please join us for the 2nd Annual Pediatric Autoimmune Liver Disease Symposium and Family Day at Cincinnati Children's.

**What can you expect from this year's conference?**

- Discuss clinically relevant information aimed at the diagnosis and treatment of Autoimmune Hepatitis (AIH) and Primary Sclerosing Cholangitis (PSC).
- **Symposium Theme: The Microbiome**—Share the latest research findings with a focus on how the gut microbiome impacts onset and progression of autoimmune liver disease.

**By attending, you'll have a unique opportunity to interact with a diverse group of ALD-informed individuals, including: patients and families, scientists, physicians and healthcare providers.**

**VIEW THE PROGRAM & REGISTER ONLINE BY VISITING:**

www.regonline.com/palds2018

**FOR MORE INFORMATION CONTACT:**

cald@cchmc.org 513-517-2051

BRV266938 0318 000700

*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.*

PSC Partners Seeking a Cure
(303) 771-5227 | contactus@pscpartners.org | pscpartners.org
6900 E Belleview Ave Ste 202, Greenwood Village CO 80111