

ARPKD/CHF Conference-“Empowering the Patient”

PLEASE JOIN US!



On Saturday November 3, 2018, the ARPKD/CHF Alliance and The Children's Hospital of Philadelphia's Division of Gastroenterology, Hepatology and Nutrition will co-host a conference.

DATE: Saturday, November 3, 2018.

WHERE: The Children's Hospital of Philadelphia, 324 S. 34th Street, Philadelphia, PA 19104-4399, in the Strokes Auditorium, located in the main building.

TIME: check-in at 10:30 am, conference from 11:00 a.m. to 7:30 p.m. Arrive a few minutes early with a governmental photo ID for lobby security.

WHO SHOULD ATTEND: parents, caregivers, teens and adults affected by this condition.

CONFERENCE FEE: \$40.00/person until October 15, 2018, includes all materials, refreshments, lunch and dinner. After October 15, 2018 registration fee increases to \$50.00/person.

(Scholarships available for those in need, please contact us for details).

A block of rooms will be held at the Holiday Inn Express Midtown-Philadelphia, located at 1305 Walnut Street, Philadelphia, PA 19107 for \$134.00/night (that does not include taxes). Parking is \$30.00/day. For a reservation call 267-765-2861, mention the ARPKD/CHF Conference. Discounted rates will only be held at this rate until October 5, 2018, after that there is a significant increase in cost.

Parking passes will be available for the CHOP parking lot.

TO REGISTER: Go to www.arpkdchf.org

AGENDA

- 10:30-11:00 am Sign-In**
- 11:00 am Welcome** – Colleen Zak, MSN, CRNP
- 11 am-12:45 pm ARPKD and ADPKD – What is Similar and What is Different?**
Moderator: Dr. Jessica Wen, MD, Hepatologist, CHOP
- 11:00-11:30 am In the Kidney: Pathology, Clinical Manifestations, Long Term Outcome**
Erum Hartung, MD, Nephrologist, CHOP
- 11:30-12:00 pm In the Liver: Pathology, Clinical Manifestations, Long Term Outcome, Understanding Liver Laboratory Results**
Andrew Wehrman, MD, Liver Transplant Fellow, CHOP
- 12:00-12:30 pm Portal hypertension, Varices, Splenomegaly, Caroli Disease**
Kathleen Loomes, MD, Transplant Hepatologist, CHOP
- 12:30-12:45 pm Q&A To The Panel**
- 12:45-1:30 pm Box Lunches provided**
- 1:30-3:15 pm ARPKD/CHF: Understanding the Unique Aspects and Challenges**
Moderators: Dr. Jessica Wen, MD, Hepatologist and Dr. Erum Hartung MD, Nephrologist
- 1:30-2:00 pm Understanding imaging ARPKD and Clinical Drug Trial update on Tesevatinib**
Erum Hartung, MD, Nephrologist, CHOP
- 2:00-2:30 pm Psychological issues of chronic illness in early life**
Kari Baber, PhD, Pediatric Psychologist, CHOP GI Behavioral Health
- 2:30-3:00 pm Supports structures/services/insurance considerations for families facing chronic illness**
Georgia Pitsakis, MSW LCSW and Christine Hall, MSW, LCSW, Social Work, CHOP
- 3:00-3:15 pm Q&A To The Panel**
- 3:15-3:30 pm Break**
- 3:30-5:15 pm Talking with your Medical Team**
Moderator - Dr. Wen, MD, Hepatologist, CHOP
- 3:30-4:00 pm Systemic Hypertension and Renal transplantation in ARPKD**
Kevin Meyers, MD, Nephrologist, CHOP
- 4:00-4:30 pm Liver transplantation in ARPKD/CHF**
Dr. Wen, MD, Hepatologist, CHOP
- 4:30-5:00 pm Post transplant care and immunosuppression**
Samantha Halpern, CRNP, MSN, Transplant Hepatology, U of Penn
- 5:00-5:15 pm Q&A To The Panel**
- 5:15-6:00 pm Panels**
Moderator-ARPKD/CHF Alliance Board Member
- 5:15-5:30 pm Parental Insight Presentations (2-5 minutes)**
- 5:30-6:00 pm Life Beyond Childhood: Adult panel, Q&A for those affected**
- 6:00-6:45 Dinner with Participatory Break Out Sessions**
1. Factions, Stronger Together then Separate? Uniting Our Disease?
 2. How to Improve Medical Outreach Education that includes Affected Adults?
 3. Engaged Patients Have Better Outcomes? How to Improve Patient Outcomes?
- 6:45-7:30 pm Keynote Address: 10 year NIH Research Update and Questions**
Theo Heller, MD, Chief, Translational Hepatology Section, Liver Disease Branch
NIDDK, National Institutes of Health

(Friday Early Bird Social: 6:00-8:00 pm McGillin's Olde Ale House, a 2-3 minute walking distance from hotel; each attendee is responsible for their own food/drinks.)