



Join PXEers, their families, clinicians, and researchers for this important meeting – don't miss receiving the latest info and networking with our community!

Sidney Kimmel Medical College
Department of Dermatology and Cutaneous Biology
PXE International Center of Excellence in Research and Clinical Care
(Established in 2016)
Philadelphia, Pennsylvania

September 28-30, 2018

At this year's meeting, you will learn about what we know about PXE and what we don't know. In addition, you will find like-minded folks who care about what you care about. We will provide opportunities to work with each other, clinicians, and researchers.

Agenda
Jefferson Alumni Hall (JAH)
1020 Locust Street

Friday Night, September 28, 2018

- 5:00 PM: **Registration**
JAH - Lobby
- 6:00 PM: **Dinner at Ristorante La Buca (711 Locust Street, 215.928.0556)**
- 7:00 PM: **Welcome and "Ride Across America", Jessica Harper,**

Saturday, September 29, 2018

Saturday morning begins with an overall orientation and introduction to PXE. Leading experts will discuss what we know and what remains to be discovered. Clinicians, researchers and affected individuals from the PXE community will lead discussions. Brainstorming, refining content and voting will help determine future questions for PXE research.

8:00 AM: **Breakfast**

JAH Atrium

9:00 AM: **Orienting Us to the Day**

JAH Eakins Lounge *Sharon Terry, CEO, PXE International*

9:15 AM: **What We Know About PXE**

JAH Eakins Lounge *Genetics: Jouni Uitto, MD, PhD*

Skin: Lionel Bercovitch, MD

Eyes: Wayne Fuchs, MD

Cardiovascular: TBD

Women's Issues: Lionel Bercovitch, MD

10:15 AM: **Break**

JAH Atrium

10:45 AM: **Research on PXE**

JAH Eakins Lounge *Jouni Uitto, MD, PhD Jon Schoenecker, MD, and András Váradi, PhD*

11:45 AM **Update on the Magnesium Trial**

JAH Eakins Lounge *Mark Lebwohl, MD, and Wayne Fuchs, MD*

12:00 PM: **Lunch**

JAH Atrium

1:30 PM – 5 PM: **Breakout Sessions**

Attendees choose Track A, B, or C. Content of Track A and B are the same.

Time	Breakout sessions		
	Track A (JAH M23)	Track B (JAH M24)	Track C (JAH M25)
1:30 PM • Session 1	Signs and symptoms	Research	Support (Break determined by the participants)
3:00 PM • Break	Break	Break	
3:30 PM • Session 2	Research	Signs and symptoms	

Signs and symptoms of PXE: You've heard the general discussion about various aspects of PXE. Now take time to share your signs and symptoms, get answers to your specific questions, and learn about nuances of aspects of PXE. *Lionel Bercovitch, MD, Wayne Fuchs, MD, Mark Lebwohl, MD and Christine Vocke, MS*

Research: PXE International has supported a great deal of research over the last 24 years, thanks to generous donors like you. We are on the verge of several breakthroughs that will have been described in the morning. This is a time to ask questions and learn more. *Jouni Uitto, MD, PhD, Jon Schoenecker, MD, András Váradi, PhD, and Patrick Terry*

Support: Using awareness and mindfulness tools, we will explore where you find support and how to sustain it. This session is interactive, we will work together in the larger group, and in pairs and trios exploring meditation, exercises to help us stay in the present moment, and practices to take with you when you need more support. *Sharon Terry and Tamara Wurst*

Note: This breakout spans Session 1 and 2 and will have its own break. In order to build on the experience, participants must join for Session 1. While we ask that you participate from 1:30 PM to 5:00 PM so that you and your fellow participants feel supported, you would be free to leave and join Session 2 should this is not meeting your needs.

5:00 PM: **Dinner on your own:** You are in the City of Brotherly Love and the Cradle of Liberty, take advantage of the historical sites of Philly, and the great local cuisine. Please visit www.visitphilly.com, the official visitor and tourism site, for restaurants, and events happening in Philadelphia during your stay. You will also receive some information in your registration materials at the door.

Sunday Morning, September 30, 2018

8:00 AM: **Breakfast**
JAH Atrium

9:00 AM: **Reports from the Breakouts**
JAH Eakins Lounge

10:00 AM: **What can we do as a community to move forward with this research agenda?**
PXEer (3 breakouts) JAH M23, JAH M24, JAH M25
JAH Eakins Lounge

11:00 AM: **Break**
JAH Atrium

11:30 AM: **Summary and Closing**
Sharon Terry, CEO, PXE International
JAH Eakins Lounge

General Information

Attire

Casual, comfortable attire is appropriate for all sessions and meals.

Cancellations

Please call PXE International's office at 202.362.9599, extension 208. Cancel by Friday, 9/14/2018, for a 100% refund. Cancel by Friday, 9/21/2018, for a 50% refund. No refund for cancellations made after Friday, 9/21/2018.

Hotel Reservations

We have reserved a block of sleeping rooms at \$134/night for Friday (9/28/2018) and Saturday (9/29/2018). ***Rooms available on a first-come, first-served basis.*** Register online: <https://tinyurl.com/pxemeeting2018> use code PXE for discount. Register by phone: [1.877.666.3243](tel:1.877.666.3243) and reference the "PXE International 2018 Member Conference."

Parking

The hotel is approximately three blocks away from the meeting location and has parking available for an extra fee. The Hamilton Parking Garage is located at 221 S. 11th Street (directly across from the meeting location) for ~\$25 per day.

Photo/Video/Contact Information Release

PXE International would like to use and distribute (including, but not limited to, use in newsletters, guides, appeals, web pages, and reports), photographs or videos taken at the PXE International 2018 Member Conference. PXE International will distribute a contact list with names and contact information **only** to PXE International 2018 Member Conference attendees. Please contact the PXE International office by email mpeck@pxe.org (Mary) or by phone (202.362.9599) if you do **NOT** wish to have your photo, video or contact information used by PXE International as described above.

Public Transportation

The hotel is about three blocks from Sidney Kimmel Medical College. Taxi service and UBER are readily available in the area.

Roommates

If you are traveling alone and wish to share a room with another attendee, note it on your registration form or contact the PXE International office by email mpeck@pxe.org (Mary) or by phone (202.362.9599).

Transportation from the Airport

The Holiday Inn Express and Sidney Kimmel Medical College are about 8 miles or 13 kilometers from the Philadelphia International Airport and taxi and UBER services are available in the area. Details for driving directions, shuttle services can be found by calling The Holiday Inn Express at [1.877.666.3243](tel:1.877.666.3243) or on the hotel's website at <https://tinyurl.com/pxemeeting2018>.

Registration Form

Register online: <https://goo.gl/forms/fkBH2XxrTdWJnJX72>

Register by phone:

202.362.9599, ext. 208

Register by fax:

202.966.8553

Register by mail:

PXE International

4301 Connecticut Avenue NW, Suite 404

Washington, DC 20008-2369

Contact

First and Last Name			
Address			
City			
State/Province		Phone	
Zip Code		Email	

Registration – List all individuals you are registering. Indicate payment on the last page.

First and Last Name	Date of Birth [mm/dd/yy]	Affected by PXE?
1.		<input type="checkbox"/> Yes <input type="checkbox"/> No
2.		<input type="checkbox"/> Yes <input type="checkbox"/> No
3.		<input type="checkbox"/> Yes <input type="checkbox"/> No

My preference is:

- Track A
- Track B
- Track C

Hotel – You are responsible for making your own hotel sleeping room reservations. We have reserved a block of sleeping rooms at \$134/night for Friday, 9/28/2018, and Saturday, 9/29/2018. ***Rooms available on a first-come, first-served basis.*** The hotel discounts PXE International's use of the large meeting rooms because we guarantee a number of sleeping rooms will be used. We pay a penalty for sleeping rooms not registered under the PXE International room block.

Discounted sleeping room rate: \$134 per night

Deadline: Friday, 9/14/2018

By phone: [1.877.666.3243](tel:18776663243) and reference "PXE International 2018 Member Conference

Online: <https://tinyurl.com/pxemeeting2018>

Staying at Holiday Inn Express? Yes No

Confirmation #:

Name of additional people sharing room:

I would like to share a room with a same-sex roommate: Yes No

Meals – Indicate the number of persons attending each meal and break.

Date	Meal	Regular	Vegetarian/ Vegan	Gluten-Free	Other
Friday, September 28, 2018	Dinner				
Saturday, September 29, 2018	Breakfast				
	Morning break				
	Lunch				
	Afternoon break				
Sunday, September 30, 2018	Breakfast				
	Morning break				

Conference Cost

Registration: On Site Registration is \$280 per person.

EARLY BIRD	REGULAR	# of People	Total
<input type="checkbox"/> \$170 (due 8/24/2018)	<input type="checkbox"/> \$230 (due 9/20/2018)	_____ =	_____
		**Tax deductible contribution – Thank you!	_____
		TOTAL PAID	_____

Payment Type

Check:

Payable to: PXE International in US dollars

Mail to: PXE International

4301 Connecticut Avenue NW, Suite 404, Washington, DC 20008-2369

Credit Card: Please print clearly. Print your name as it appears on the credit card.

Card type:	<input type="checkbox"/> American Express <input type="checkbox"/> MasterCard <input type="checkbox"/> Visa <input type="checkbox"/> Discover
Card #:	Expiration Date (mm/dd/yy):
Print name:	Signature:

Or pay online:

Paypal.me/pxe