

You are invited to attend the free one-day event

# Hermansky-Pudlak Syndrome Patient Education Day

Saturday, April 27, 2019 at the Courtyard by Marriott Isla Verde

## About

You are invited to a free Hermansky-Pudlak Syndrome (HPS) patient education seminar to be held on Saturday, April 27, 2019. This event is co-sponsored by the American Thoracic Society, the Hermansky-Pudlak Syndrome Network, the San Juan City Hospital and the Mayaguez Medical Center Pulmonary Fibrosis Clinic. This event is being held in conjunction with the "HPS Week at the ATS" program — an educational activity designed to foster interaction between clinicians, patients and patient advocates on lung and airway disorders and other health concerns associated with HPS.

**Where:** Courtyard by Marriott Isla Verde  
7012 Calle Avenue Boca de Cangrejos  
Carolina, Puerto Rico 00979

**When:** Sat, April 27, 9:00 a.m. to 4:00 p.m.

**Who:** Open and free to all individuals with HPS, their family members and health care providers. It is also open to the interested general public.

## Program

9:00–9:30	Continental Breakfast / Information & Resource Tables
9:30–10:00	Registration
10:00–10:15	<b>Welcome from the American Thoracic Society (Mr. Courtney L. White)</b>
10:00–10:15	<b>Welcome from the San Juan City Hospital (Maria Christina Betancourt, MD)</b>
10:00–10:15	<b>Welcome from the Mayaguez Medical Center Pulmonary Fibrosis Clinic (Rosa Roman, MD)</b>
10:15–10:30	HPS Network Year in Review (Donna Appell RN)
10:30–11:15	Hermansky-Pudlak Syndrome Pulmonary Fibrosis (Bernadette Gochuico, MD)
11:15–12:00	Bleeding Issues of HPS (Enid Rivera, MD)
12:00–1:00	Lunch Break

### Afternoon session for adults with HPS

1:00–1:45	Puerto Rico Pulmonary Fibrosis Clinic – HPS (Rosa Roman, MD)
1:45–2:30	Lung Transplantation (Jesse Roman, MD)
2:30–3:00	Living with HPS and the Transplant Information and Peer Support (TIPS) Program (Carmen Camacho)
3:00–3:30	Questions and Answers

### Afternoon session for parents of children with HPS

1:00–1:45	Caring for Young Lungs (Wilfredo de Jesus Rojas, MD)
1:45–2:30	Advocating for Your Child in School (Sofia Pantel)
2:30–3:15	Updates – Office of the Patient Advocate, PR (Edna Díaz, MSA, BHS)
3:00–4:00	Family Circle (Coralys Santiago)



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## Speakers

### **Bernadette Gochuico, MD**

Senior Research Physician and Attending  
Pulmonologist  
National Human Genome Research Institute  
National Institutes of Health, MD

### **Maria Christina Betancourt, MD**

Pulmonary/Critical Care  
Program Director, Pulmonary Fellowship  
Training  
San Juan City Hospital

### **Rosa Roman, MD**

Clinical Director  
Pulmonary Fibrosis Clinic, Mayaguez Medical  
Center  
Mayaguez, PR

### **Jesse Roman, MD**

CEO of the Jane and Leonard  
Korman Respiratory Institute,  
a collaboration of Jefferson Health and  
National Jewish Health  
Thomas Jefferson University Hospitals,  
Philadelphia, PA

### **Wilfredo de Jesus Rojas, MD, FAAP**

Pediatric Pulmonologist  
Ad-Honorem Assistant Professor  
Department of Pediatrics  
University of Puerto Rico, School of Medicine

### **Sofia Pantel**

Director PRATP  
Accesible Tecnología Programa PR

### **Edna Díaz, MSA, BHS**

Advocate  
Office of the Patient Advocate, Puerto Rico

### **Coralys Santiago**

PhD Candidate, Clinical Psychology  
Carlos Albizu University  
San Juan, PR

### **Nancy Lee**

Patient Speaker  
Board of Directors, HPS Network, Inc.

### **Donna Appell, RN**

Executive Director and Founder  
HPS Network, Inc.

### **Carmen Camacho, MA, LSW**

Member, Board of Directors  
Director, Transplant Information and Peer  
Support (TIPS)  
HPS Network, Inc.



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