

You are invited to a **Free Hermansky-Pudlak Syndrome** seminar on
Saturday, March 28, 2015 entitled
**Hermansky-Pudlak Syndrome
Patient Education Day**

The American Thoracic Society (ATS), the Hermansky-Pudlak Syndrome Network (HPS Network) and the San Juan City Hospital (Puerto Rico) presents a free one day patient-education seminar on Hermansky-Pudlak Syndrome. This event is being held in conjunction with the “Rare Lung Diseases Week at the ATS” program — an educational activity designed to foster interaction between clinicians, patients and patient advocates on lung and airway disorders.

WHERE San Juan City Hospital - Auditorium, 185 Costa Rica Street, San Juan, PR 00936

WHEN Sat, March 28th from 9:00 a.m. to 3:00 p.m. (AST)

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. A light breakfast and complimentary lunch will be provided.

If you would like to attend this event please RSVP by email to Ms. Donna Appell, RN of the HPS Network at dappell@hpsnetwork.org no later than Monday, March 23, 2015. Space is limited so please respond early.



Hermansky-Pudlak Syndrome Patient Education Day

PROGRAM

9 - 10 a.m. Registration and light breakfast

10 - 10:30 a.m. Welcome from the American Thoracic Society *Mr. Courtney L. White*
Welcome from the HPS Network *Donna Appell, RN*
Welcome from the San Juan City Hospital *Ricardo Fernandez, MD*

10:30 - 11:15 a.m. Hermansky-Pudlak Pulmonary
Fibrosis *Bernadette Gochuico, MD*

11:15 a.m. - 12 p.m. Lung Transplantation *Fernando Torres, MD*

12 - 1 p.m. LUNCH

1 - 1:45 p.m. Pulmonary Fibrosis Genotype-Phenotype Correlations in the
Puerto Rican Population with Hermansky-Pudlak Syndrome Type-1
Yeidyly Vergne, MPH, DrPH

1:45 - 2:30 p.m. Being Part of the Solution: Research Matters
Carmen Camacho, MA, LSW

2:30 - 3 p.m. Question & Answer session

SPEAKERS

Bernadette Gochuico, MD
Attending Pulmonologist
National Human Genome Research
Institute
National Institutes of Health

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

Fernando Torres, MD
Head, Lung Transplant and Pulmonary
Hypertension Programs
UT Southwestern Medical Center

Yeidyly Vergne, MPH, DrPH
Ponce School of Medicine and Health
Sciences

Donna Appell, RN
Founder and CEO
HPS Network, Inc.

Carmen Camacho, MA, LSW
Board of Directors
New England Regional Coordinator
HPS Network, Inc.