

The 16th Annual

Hermansky-Pudlak Syndrome

Network Conference

“The Hero Inside of you!!”

You have the **POWER!**

*Supporting Individuals, Families, Partners,
Professionals and Friends !!!!*

Join us in the fight
to find a cure!

There's a
Hero in you!



March 20-22, 2009

Marriott Hotel
Uniondale, Long Island
New York

“The Hero Inside of You”

creates opportunities of a lifetime;
to give you the **POWER** to dream,
to love, to care, to be cared for,
and the **POWER** to believe that
we will be cured!

The 16th Annual HPS Conference
“The Hero Inside of You”
March 20-22, 2009



One South Road
Oyster Bay, New York 11771-1905

PRELIMINARY CONFERENCE SCHEDULE

Friday, March 20, 2009

- 2:00PM Conference Registration Begins
- 4:00PM Development / Fundraising
- 5:00PM HPS Presentations in a Box
- 6:00PM Casual Dinner in the Hospitality Suite
- 7:00PM HPS Annual Update – Adult attendees
(Child Care available for ONE Hour)
- 8:00PM Family Game Night
Young Adults Dinner
HPS Network Puerto Rico Meeting

Saturday, March 21, 2009

- 9:00AM - 4:00PM OPEN for:
 - Registration and Child Care
 - Our Family Album: Getting to Know You
 - Science Track: Vision Issues, Genetics,
Gynecology and Women's Health
 - Psychosocial Track: Coping Circles, Yoga
Stress Management, Makeup Session

HPS CONFERENCE DINNER

- 6:00PM Ballroom
Cash Bar, Great Food, DJ, & Dancing
(price included in registration fee)

For those not registered with the conference
\$45.00 per adult / \$25.00 per child

Please note that children ages 15 and under will be served a KIDS MEAL

PRELIMINARY CONFERENCE SCHEDULE

Sunday, March 22, 2009

7:30AM **Sunrise Sessions-Interfaith Meditation**

9:00AM-4:00PM

Medical / Scientific Sessions

*Learn about Life with HPS from the
HPS Board of Directors*

Research Updates- Dr. William Gahl, Clinical
Director of National Human Genome Research
Institute (NHGRI)

Lung Protocol- Dr. B. Gochuico,
Pulmonologist, NHGRI

Multi-drug Protocol- Dr. T. Markello,
Genetics, NHGRI

Lung Transplant- Learn from the experience of an
HPS Network Member

American Thoracic Society and HPS Network

Research Grant Recipient Update

Dr. Lisa Young, University of Cincinnati

Clinical Care- Acid Reflux, Sleep Apnea, Bleeding
Issues, Preventive Health Management

Dr. S. Seward, Columbia University, NY;

Dr. J. Markowitz, Schneider's Children Hospital, NY
(invited); Dr. M. Padilla, Mount Sinai Medical
Center, NY (invited)

Submit your questions for the doctors NOW

Send them in with your registration

.....and more.

Spanish Translation Services will be provided

KIDS KONFERENCE

Saturday, March 21, 2009

Ringling Brothers & Barnum & Bailey Circus
Next door at Nassau Coliseum !!!
5-17 yrs old

Sunday, March 22, 2009

Bowling Alley Trip, Pool Party
(please bring bathing suits)

Child care will be provided by volunteers however parents are ultimately responsible for their children. There will always be child care available back at the hotel for those who do not want to go on field trips.

CHILD CARE

Child care assistance will be offered from 9:00AM-4:00PM on Saturday and Sunday. Please reserve space for your children in advance on the registration form. Understand that our child care providers are all volunteers and that each family is ultimately responsible for their own children. We will provide activities and plenty of supervision. The children will have a wonderful time. Your cooperation is needed to support our volunteers.

HOTEL

SAVE MONEY WITH EARLY REGISTRATION

Call the HOTEL

and

make your reservation NOW!!!!

Conference Location:

Long Island Marriott Hotel
101 James Doolittle Boulevard
Uniondale, NY 11553
516-794-3800/800-228-9290

All reservations must be made no later than
Monday, March 2nd to ensure the conference
price!!

Hotel Registration:

A limited number of rooms have been set aside for the HPS NETWORK. Special room rates for our conference attendees are \$150.00 plus tax, per room, per night. To ensure that you are properly charged, you **MUST** request the group rate for Hermansky-Pudlak Syndrome Network.

Reservations may be cancelled up to 6:00PM on day of arrival or one night room rate will be charged. Check-in time is 4:00PM; check-out by 12 noon. Attendees arriving before check-in time will be accommodated as rooms become available.

CONFERENCE FEES/INFORMATION

Early Registration: through March 2nd

Adults - \$65.00

Children under 12 - \$30.00

Family of Four - \$200.00

After March 2nd

Adults - \$75.00

Children under 12 - \$50.00

Family of Four - \$250.00

Conference registration includes all food

In an attempt to keep the conference price as low as possible some of our food is donated. We appreciate all the members who help us with these donations. Please bring special meal items that your family might need and extra food for those family members with BIG appetites!

The Saturday night Family Gala Dinner will serve all attendees 15 YEARS and YOUNGER A "KIDS MEAL."

Join us for Continental Buffet Breakfast (Bagels, Danish, Cereals, Fruit, Coffee and Tea) available in the Hospitality Suite on Saturday and Sunday morning beginning at 8AM.

DONATIONS

The cost of food & the circus are not completely covered by the registration fees. If anyone is able to sponsor a family or make a donation, please call the Network at 1 (800) 789-9477.

DRIVING DIRECTIONS

From Manhattan, and points West:

Midtown Tunnel to Long Island Expressway (Rt. 495) East to Exit 38 Northern State Parkway to Exit 31A Meadowbrook Parkway South to Exit M4 Nassau Coliseum. You will see the Marriott Hotel.

From LaGuardia Airport:

Grand Central Parkway East to Northern State Parkway to exit 31A Meadowbrook Parkway South to exit M4 – Nassau Coliseum.

From Kennedy Airport:

Belt Parkway East to Southern State Parkway East to Exit 22N Meadowbrook Parkway North to Exit M4 – Nassau Coliseum.

If you are coming by train:

Take Long Island Railroad (LIRR) at New York Penn Station to Westbury Train Station, in Long Island

Taxis are available at the train station.

All Seasons Transportation—1 (516) 333-3131 \$8.00 for one person.

REGISTRATION FORM

Any questions please call: 800-789-9477 or 516-922-4022
 E-mail: info@hpsnetwork.org Website: www.hpsnetwork.org

Please return no later than Monday, **March 2nd**

HPS Network, Inc.
 One South Road, Oyster Bay, NY 11771-1905

PLEASE BE SURE TO COMPLETE THE ENTIRE FORM !!!

- I will attend Friday, Saturday and Sunday.
 I will ONLY attend on Sunday (Medical Lectures).
 I am unable to attend but I would like to make a donation.

NAME: _____

Address: _____

Phone: _____ e-mail: _____

Professional Field / Agency: _____

TOTAL NUMBER IN PARTY: ADULTS: _____ CHILDREN: _____

EARLY REGISTRATION (through March 2)

	FEE per Person		# of Persons		SUBTOTAL
ADULTS	\$65.00	X	_____	=	_____
CHILDREN (12 & UNDER)	\$30.00	X	_____	=	_____
CIRCUS TICKETS (AGES 5-17)	\$10.00	X	_____	=	_____

REGISTRATION AFTER March 2

	FEE per Person		(No. Attending)		SUBTOTAL
ADULTS	\$75.00	X	_____	=	_____
CHILDREN (12 & UNDER)	\$50.00	X	_____	=	_____
CIRCUS TICKETS (AGES 5-17)	\$10.00	X	_____	=	_____

DONATION FOR RESEARCH OR TO SPONSOR A FAMILY = _____

GRAND TOTAL = _____

	NAMES OF ATTENDEES	AGE (IF UNDER 25)	NEED CHILDCARE?
1			
2			
3			
4			
5			
6			

REGISTER NOW

**Send Registration form and checks payable
to the HPS Network to:**

**HPS Network, Inc.
One South Road
Oyster Bay, NY
11771-1905**

**Help the Network and
register early!!**

**In today's economy many may be wondering if you can
continue to participate in the conference.**

Here are some suggestions:

- make a presentation to your local Lions Club**
- ask your Commission for the Blind or the Lighthouse**
- ask your local Chamber of Commerce, Rotary Clubs,
Boys and Girls Clubs and religious organizations**
- some medical insurance companies cover medical lec-
tures**
- check to see if Conference travel and expenses
can be tax-deductible as medical education**