Spreading 19, the News

Hampstead, NH 03826

Experience the fellowship of the albinism community





Saturday, March 19, 2011 Long Island Marriott, Uniondale



# The Educational Sessions You've Been Waiting For

- Latest in Albinism Eye Research
- Skin Care
- Genetics of Albinism
- Careers Panel
- Adult and Parent Discussion Groups



### Fun for Kids!

Attendees ages 5 to 17, prepare to the see the "Greatest Show on Earth!", the Ringling Brothers and Barnum & Bailey Circus at the Nassau Coliseum (just across the street from the hotel)! What could be more fun than an afternoon at the circus with friends old and new from the albinism community? On-site activities for younger children will also be provided. Bring the whole family!

to the Circus!

# <u>Affordable Registration Fees!\*</u>

Mini-conference registration includes educational sessions, discussion groups, children's activities and lunch.

	Members	Non-Members
Adults 18 & older	\$35	\$45
Children		
Ages 5-17 (includes circus)	\$25	\$35
Ages 2-4 (or no circus)	\$10	\$20
Under age 2	FREE	\$10



# **Transportation**

### Need A Ride? Give A Ride!

Begin to enjoy the company of a new friend from the albinism community **BEFORE** the mini-conference begins! Take part in the NOAH "Need A Ride? Give A Ride!" program. If you're in need of a ride or willing to give an adult a ride, check off the box on your registration form and we'll work to connect you! It's a great opportunity to begin making connections and to help make the conference accessible for someone who might not otherwise be able to attend.

### LIRR

NOAH will provide free rides from two nearby LIRR stations:

### **Arriving:**

- eastbound train arriving at Westbury at 8:05 am
- eastbound trains arriving at Hempstead at 7:35 am and 8:35 am
- eastbound arriving at Westbury at 7:58 AM and arriving at Hempstead at 8:19 am

### Departing:

- westbound train leaving Westbury at 4:58 pm and 5:05 pm
- eastbound train leaving the Hempstead station at 5:19 pm and 5:35 pm

Please make sure that you mark your registration form should you need a ride from one of these stations. The schedules change March 6, 2011. For current LIRR schedules and fare information go to www.mta.info.

# Nationally Renowned Presenters

Look! National presenters at our regional mini-conference!

### Aisha Sethi, MD

Aisha Sethi is an Assistant Professor of Medicine at the University of Chicago Section of Dermatology. Dr. Sethi is interested in tropical and traveler's dermatology syndromes in business and recreational travelers, immigrant and minority populations, as well as global infectious diseases with dermatologic manifestations. This has led her to field



work in Pakistan, St. John's Institute of Dermatology and the Hospital for Tropical Diseases in London, as well as the Regional Dermatology Training Center (RDTC) in Tanzania. She is especially interested in addressing global access to medical care, as well as collaborating with educational institutions in developing countries to improve the availability and quality of medical training and dermatologic therapies. Her work in Malawi led to the first national awareness day for albinism that was held in the capital city of Lilongwe in 2007 with the advent of a weekly dedicated albinism clinic. More recently, her albinism awareness work in Malawi has been featured by national media in the country of Malawi and reported in the University of Chicago Magazine.



## Murray H. Brilliant, Ph.D.

Murray H. Brilliant, Senior Scientist, is the Director at the Center for Human Genetics at the Marshfield Clinic Research Foundation and holder of the James Weber Endowed Chair from December 2009. Dr. Brilliant has 25 years of experience in the molecular genetics of mice and humans. In particular, his efforts have led to the identification of three genes for

albinism: Hermansky-Pudlak syndrome 1 and Oculocutaneous albinism types 2 and 4. Dr. Brilliant has two current research projects on albinism: one focused on a novel form of gene therapy called "gene correction" and another, in collaboration with Dr. Gail Summers, on a clinical trial aimed at improving vision in people with albinism.

# Register Today!

NOAH is committed to bringing the magical experience of the albinism community to as many people as possible. The New York Mini Conference is a jam-packed day featuring top experts in the field, meaningful panels and discussion groups and the opportunity for kids to be kids amongst the albinism community.

Be a part of the NOAH magic! Register by Monday March 2nd!

# **Location Information**

Long Island Marriott Hotel and Conference Center 101 James Doolittle Boulevard Uniondale. New York 11553 USA



Phone: 1-516-794-3800

Group rate: \$150 per night, double occupancy (mention HPS Network)

2 miles from the Westbury Station on the Long Island Rail Road



# Volunteer with the Kids!

If you are a *fun*, *enthusiastic*, *responsible* person who *loves kids*, then NOAH may be looking for you! NOAH is seeking a limited number of volunteers to help with supervision during the mini conference. If you'd like to be considered, email info@albinism.org or call 800-473-2310 for more details.

# <u>Special Thanks</u>

Special thanks to Donna Appell, president and founder of the HPS Network, and tireless NOAH board member, for partnering with NOAH on this mini conference.

# Mini-Conference Registration

Please clearl	arly and legibly	PRINT	ALL	registration i	information
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