



# NATIONAL CONFERENCE on HISTIOCYTIC DISORDERS

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# ORLANDO 2007

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## REVISED MEETING AGENDA

### Tuesday July 31, 2007

6:00 – 9:00 **Evening Welcome Reception on the Hotel Deck**  
*Hosted by Jeffrey M. Toughill, President - Histiocytosis Association of America*

### Wednesday, August 1, 2007

9:00 – 9:15 **Opening Ceremonies**  
*Jeffrey M. Toughill, President – Histiocytosis Association of America*

9:15 – 9:45 **Histiocytic Disorders Overview**  
*Dr. R. Maarten Egeler – Leiden University Medical Center, The Netherlands*

9:45 – 11:00 **Caring and Sharing Session**  
*Jeffrey M. Toughill, President – Histiocytosis Association of America*

11:00 – 11:15 **Break**

11:15 – 12:30 **Langerhans Cell Histiocytosis Session Part I**  
LCH in Neonates  
*Dr. Sheila Weitzman – The Hospital for Sick Children, Toronto, Canada*  
  
Central Nervous System Involvement  
*Dr. James Whitlock – Vanderbilt University Medical Center, Nashville, Tennessee USA*  
  
Endocrine-related Issues  
*Dr. Vasanta Nanduri – Watford General Hospital, United Kingdom*

11:15 – 12:30 **Hemophagocytic Syndromes Session (Networking Lounge Room)**  
*Dr. Alexandra Filipovich – Cincinnati Children's Hospital, Cincinnati, Ohio USA*

12:30 – 2:00 **Networking Luncheon**

2:00 – 3:15 **Langerhans Cell Histiocytosis Session Part II**  
Bone Involvement  
*Dr. Sheila Weitzman – The Hospital for Sick Children, Toronto, Canada*  
  
Reactivation in LCH (low-risk, multi-system and high-risk)  
*Dr. Milen Minkov – St. Anna Children's Hospital, Vienna, Austria*  
  
Long-term Effects  
*Dr. Vasanta Nanduri – Watford General Hospital, United Kingdom*

3:15 – 3:30 **Break**

3:30 – 4:45 **Rare Histiocytic Disorders Workshop**  
Rosai-Dorfman Disease, Erdheim Chester Disease, and Juvenile Xanthogranuloma  
*Dr. Sheila Weitzman – The Hospital for Sick Children, Toronto, Canada*  
*Dr. James Whitlock – Vanderbilt University Medical Center, Nashville, Tennessee USA*

4:45 – 6:00 **Exhibit Viewing and Networking**

**Thursday, August 2, 2007**

- 9:00 – 9:45 **Histiocytosis Association of America Research Program Update**  
*Dr. Kenneth McClain – Texas Children’s Clinical Care Center, Houston, Texas*
- 9:45 – 10:30 **Funding a Cure Session**  
*Histiocytosis Association of America Staff and Volunteers*
- 10:30 – 10:45 Break
- 10:45 – 12:00 **LCH in Adults Session**  
*Dr. R. Maarten Egeler – Leiden University Medical Center, The Netherlands*  
*Dr. Sheila Weitzman – The Hospital for Sick Children, Toronto, Canada*  
*Dr. Kenneth McClain – Texas Children’s Clinical Care Center, Houston, Texas*  
*Dr. Robert Vassallo – Mayo Clinic, Rochester, MN*
- 10:45 – 12:00 **Discussion Group: Raising Awareness and More (Networking Lounge Room)**  
*Histiocytosis Association of America Staff and Volunteers*
- 12:00 – 1:15 **Networking Luncheon**
- 1:15 – 2:30 **Clinical Trials and Treatment Protocol Update Part I**  
LCH–III (Langerhans Cell Histiocytosis); LCH–CNS (Central Nervous System)  
*Dr. Milen Minkov – St. Anna Children’s Hospital, Vienna, Austria*
- LCH–S (Salvage)  
*Dr. Carlos Rodriguez-Galindo – St. Jude Children’s Research Hospital, Memphis, Tennessee*
- 2:30 – 2:45 Break
- 2:45 – 4:00 **Clinical Trials and Treatment Protocol Update Part II**  
LCH–BMT/HCT (Bone Marrow Transplantation); LCH–A (Adult Patient)  
*Dr. R. Maarten Egeler – Leiden University Medical Center, The Netherlands*
- HLH–2004 (Hemophagocytic Lymphohistiocytosis)  
*Dr. Alexandra Filipovich – Cincinnati Children’s Hospital, Cincinnati, Ohio*
- 6:00 – 10:00 **Polynesian Luau Dinner Banquet**  
*Paradise Cove at Buena Vista Watersports – Lake Bryan, Buena Vista, Florida*
- Meet in Lobby at 5:30 PM to board transportation shuttles to Paradise Cove*

**Friday, August 3, 2007**

- 10:00 – 11:00 **Patient Care Session**  
Caring for a Patient at Home; Tips for Patient Care During and After Treatment  
*Sharon Miller, RN*
- 11:00 – 11:15 Break
- 11:15 – 12:15 **Psychosocial Effects of a Rare Disease**  
Effects of a Rare Disease on the Family, Caregiver Issues  
*Kevin P. Putansu, LCSW - University of Florida Health Sciences Center, Gainesville, Florida*
- 12:15 – 1:30 **Networking Luncheon**
- 1:30 – 3:00 **Meet the Experts Question & Answer Session**  
*Dr. Alexandra Filipovich, Dr. Milen Minkov, Dr. Vasanta Nanduri,*  
*Dr. Carlos Rodriguez-Galindo, Dr. Amir Shahlaee, and Dr. James Whitlock*
- 3:00 – 3:15 **Closing Ceremonies**

SCHEDULE SUBJECT TO CHANGE WITHOUT NOTIFICATION