

Hosted by: Baylor College of Medicine, Texas Children's Hospital, and The Blue Bird Circle Rett Center

Hilton Plaza Hotel - Medical Center | 6633 Travis Street | Houston, Texas 77030 | 1-800-HILTONS (1-800-445-8667)

★ *For hotel reservations:* http://www.hilton.com/en/hi/groups/personalized/H/HOUMCHF-MECP-201250923/index.jhtml?WT.mc_id=POG
 24hr Reservations Department @ 1-800-HILTONS (1-800-445-8667) | Ask for the group by name: **MECP2 Duplication Syndrome**
 or the **Group Code: MECP** | Reservations must be made on or before the cutoff date of: **09/02/2015.**

★ *To register online for the conference:* www.bcm.edu/mecp2-conference

— CONFERENCE SCHEDULE —

[**WEDNESDAY, Sept. 23 @ 6:30pm**] - *Meet & Greet / Welcome Dinner -*
 • Location—8th floor conference room area

[**THURSDAY, Sept. 24th (AM)**
 8:00am: BREAKFAST - 8th Floor
 - *Basic Science -*]

• **8:45am: Introduction & Natural History Study**

- Dr. Bernhard Suter
 - Dr. Sarika Peters

• **9:00am: Overexpression of Methyl-CpG Binding Protein 2 Impairs Th1 Responses & Type I Immunity** - Dr. David B. Corry

• **9:45am: Synaptic Plasticity**

- Dr. Colleen Niswender: Metabotropic glutamate receptor 7: a new therapeutic target for both Rett and MECP2 Duplication syndromes

- Dr. Rocco Gogliotti: Protein synthesis dependent synaptic plasticity in MECP2 related disorders

• **10:45am: Small Molecule Therapeutics Part I— Screening:** - Dr. Lauren Lombardi: Identifying druggable modulators of MECP2 levels

Part II— ASOs: - Dr. Ezequiel Sztainberg: Progress in the research of potential antisense oligonucleotide therapy for MECP2 duplication syndrome

• **11:45am: Fund Raising Efforts**
 - Collene Wright,
 The Van Wright Foundation

[**THURSDAY, Sept. 24th (PM)**
 12:00 - 1:00pm; LUNCH
 - *Current Clinical Management -*]

• **1:00pm: GI/Nutrition**

- Dr. Kathleen J. Motil: Nutrition and Gastroenterology for MECP2 Duplication

• **1:30pm: PM&R**

- Dr. Daniel Glaze: Achieving a Good Night's Sleep for Parents and Their Children

• **2:00pm: Sleep Medicine**

- Dr. Aloysia Schwabe: Rehabilitation Considerations in MECP2 Duplication Syndrome

• **2:30pm: Pulmonary**

- Dr. Marianna Sockrider: Breathing-Related Complications in MECP2 Duplication Syndrome

• **3:00pm: Epilepsy**

- Dr. Rebecca Schultz: Management of Refractory Epilepsy

• **3:30pm: Motor**

- Dr. Bernhard Suter: Motor Dysfunction in the MECP2 Duplication Syndrome

• **4:00PM:**
 * *NRI lab tour-Dr. Zoghbi* *

6:30pm
 - *Wine & Cheese Reception -*
 Sponsored by: Pete Anderson / Collene Wright

[**FRIDAY, Sept. 25th (AM)**
 8:00am: BREAKFAST - 8th Floor
 - *Resources / Family Issues -*]

• **9:00am: Assistive Devices**

- April Brackett: Augmentative Communication

• **9:30am: Navigating the Healthcare System**

- Diane Murrell; Helen Murray

• **10:30am: Practical Tips for Parents**

- Dr. Sherry Vinson

• **11:00am: Coping Mechanisms**

- Dr. Sarika Peters

• **11:30am: Internet Visibility/Foundation**

- Family Representatives
 - Dr. Suter; Dr. S. PeterS

• **11:50am: Wrap-Up & Future Outlook**
 - Dr. Bernhard Suter

• **12:00PM - 2:30PM:**
 * *Focus Group Lunch w/ Survey* *

— CONTACTS —

For Questions:

CONTACT: Gay Fullerton

phone: 832-822-7388 or toll-free: 1-888-430-7388

email: gayf@bcm.edu or gfuller@texaschildrens.org

Sibling Tour Information: - **CHAPERONES NEEDED!!** -

CONTACT: Amy Moore

phone: (214) 533-2158 / email: mooreamy1@sbcglobal.net

- COST = \$35 + extra money for spending/snacks

• **FIGHTING TO CURE MECP2 DUPLICATION** •

* *Sponsored by:* The 401 Project • The Blue Bird Circle • The Taylor Family Foundation *