

Preliminary Conference Schedule

June 20-23, 2018; St. Louis, MO

Day:	Time:	Event:
Wednesday PM	1:00 – 5:00	Registration
	3:00 -3:15	Welcome
	3:15 – 4:30	Panel discussion: Best Clinical Practices in CCHS. Moderator: Dr. Maida Chen <i>CCHS experts from US/International community talk about CCHS and answer patient/family questions/top concerns/top care issues.</i> Dr. Piumelli (Italy), Dr. Samuels (UK), Dr. Sivan (Israel), Dr. Keens, Dr. Trang, Dr. Frerick (Germany)
	4:30 – 4:45	Break
	4:45 – 5:15	CCHS Network One World Registry: Talk and Q/A period with members
Thursday AM		
	9:00 am – 4:00 pm	Tech Fair
	9:00 – 9:40	Molecular Drug Targets in CCHS Dr. Isabella Ceccherini M.D., UOC Genetica Medica Istituto Giannina Gaslini
	9:40 – 9:50	Break
	9:50 – 10:30	Molecular Biology of Respiratory Drive: Undoing Ondine Dr. Douglass Bayliss, Ph.D., University of VA
	10:30 – 10:40	Break
	10:40 – 11:20	PHOX2B and the Genes It Controls Dr. Diego Fornasari , M.D., Ph.D., University of Milan
	11:20 – 11:30	Break
	11:30 - noon	Isabella, Diego, Doug panel discussion
Thursday PM	1:00 – 2:15	Poster Session
	2:15 – 2:30	Break
	2:30 – 3:10	French Presentation, Dr. Ha Trang, M.D., Hôpital Robert Debré
	3:10 – 3:20	Break
	3:20 – 5:00	Transitions in CCHS: Small Group Discussions. Moderator: Sheila Kun, RN, BSN, BA, MS, CPN, FCCP, Nurse Care Manager, Pediatric Pulmonology CHLA – 10 minute introduction. 30 minute repeating sessions between 3:30 – 5:00. <i>Transition to non-invasive ventilation: 2 separate talks – 1 on pacers the other on BiPap</i> <i>Starting a family</i> <i>YA Discussion (limited to YA population)</i> <i>Going to school</i> <i>Fostering independence</i>
	1:00 – 5:30	Research Fair
	5:00 – 5:15	Day 2 summary/wrap-up
Friday AM		
	9:00 am – 4:00 pm	Tech Fair
	9:00 – 9:40	Inhibition of HSP90 in Mice: Respiratory Function Recovery Dr. Namasivayam Ambalavanan, M.D., University of Alabama at Birmingham
	9:40 – 9:50	Break

	9:50 – 10:30	Diaphragm Pacing: Phrenic Nerve Stimulation Dr. Cathy Shin, M.D., CHLA
	10:30 – 10:40	Break
	10:40 – 11:20	3 Generations of Same PHOX2B Mutation But Different Phenotype Dr. Ajay Kasi, M.D., Children’s Healthcare of Atlanta
	11:20 – 11:30	Break
	11:30 – 12:10	Clinical Practice in Israel: Dr. Yakov Sivan, M.D., Dana Children's Hospital, Tel Aviv Sourasky Medical Center
Friday PM	1:10 – 1:50	Clinical Practice in Japan: Diagnosis and Treatments Dr. Yosuke Yamada, M.D., Japan
	1:50 – 2:00	Break
	2:00 – 2:40	Neurocognitive Functioning in CCHS Patient Dr. Debra Weese-Mayer, M.D., Lurie Children’s Hospital
	2:40 – 2:50	Break
	2:50 – 3:30	Concurrent Talks– attendee pick. 1. Dr. Sabrina Tsao, M.D., Lurie Children’s Hospital (Cardiologist); 2. Dr. Jose Garza, M.D., Children’s Healthcare of Atlanta (HD)
	3:30 – 3:40	Break
	3:40 – 4:40	Concurrent Panels 1. Best Practices in CCHS Care Take 2: Moderator – Dr. Iris Perez, M.D., CHLA Clinical Panel: Cardiology, Pulmonology, Endocrinology, Gastro-intestinal, Neurocognitive 2. Research Panel: Moderator – Dr. Eddy Yang, M.D., Ph.D, UAB, Father of CCHS patient
	4:40 – 5:00	Day 3 Summary/Wrap-up
Saturday AM		
	9:00 – 9:45	CCHS Patient Panel – Loud and Proud: Hear from the Real Experts About CCHS
	9:45 – 10:00	Break
	10:00 – 11:00	Round Table Discussion of Issues Important to Families – Moderator – Dr. Thomas Keen, M.D., Children’s Hospital Hospital Los Angeles Researchers/clinicians/CCHS Experts
	11:00 – 11:15	Break
	11:15 – 12:15	Wrap up/conclusions