**5th International CCHS Conference: *The Future is NOW*  
*Priorities, Partnerships, and Patient Voice***

***June 20-23, 2018***

***Chase Park Plaza, St. Louis, MO***

[**www.chaseparkplaza.com**](http://www.chaseparkplaza.com)

The CCHS Network, Children’s Hospital, Los Angeles, Seattle Children’s Hospital, and the European Union Congenital Hypoventilation Syndrome (EUCHS) organizationwill be hosting the 5th International CCHS Research Conference at the Chase Park Plaza Hotel in St. Louis, MO, June 20 – 23, 2018 ([www.chaseparkplaza.com](http://www.chaseparkplaza.com)). The focus of this meeting will be developments in CCHS research, advances in clinical management, and progressions in CCHS living. Over the last several years research into the basic biology of CCHS and respiratory drive have exposed some of the etiology of CCHS (Kumar et al., 2017; Joubert et al., 2016), clinical advancements have enriched patient outcomes (Diep, 2015), and individuals living with CCHS have flourished. The 5th International CCHS Research Conference will target collaboration among CCHS researchers, clinicians, and patients to advance understanding and treatment of CCHS. CCHS professionals and CCHS families are invited to attend.

The 2018 conference will represent the 5th international gathering of the CCHS rare disease community. These historical meetings have fostered a supportive and collaborative CCHS union between professional and family populations, all with the intent of improving outcomes for CCHS patients. The 2018 Conference planning committee is a diverse team of CCHS experts and CCHS Family Network leaders.

CCHS clinicians and researchers from the United States and around the world will be in attendance. Speakers include Dr. Doug Bayliss, Ph.D., University of Virginia; Dr. Isabella Ceccherini, M.D., UOC Genetica Medica Istituto Giannina Gaslini; Dr. Maida Chen, M.D., Seattle Children’s Hospital; Dr. Diego Fornasari, M.D.,Ph.D., University of Milan; Dr. Thomas Keens, M.D., Children’s Hospital, Los Angeles; Dr. Iris Perez, M.D., Children’s Hospital, Los Angeles; Dr. Martin Samuels, M.D., Great Ormond Street Hospital, United Kingdom; Dr. Yakov Sivan, M.D., Dana Children's Hospital, Tel Aviv Sourasky Medical Center, Israel; Dr. Ha Trang, M.D., Ph.D., Diderot University, Paris; Dr. Debra Weese-Mayer, M.D. Lurie Children's Hospital; and Dr. Yamada, M.D., Japan, as well as other leaders in the CCHS community. Presentation and workshop themes cover a wide range of topics: “Important Transitions in CCHS”, “Penetrance and Phenotype in CCHS”, “Molecular Advancements in CCHS”, “Translational Therapies”, and “Improving Patient Outcomes”. A more detailed list of speakers and presentation topics will be available mid-fall at the CCHS Network website ([www.cchsnetwork.org](http://www.cchsnetwork.org)).

**Call for Abstracts**

***We welcome proposals from the research, clinical, allied health, and family communities***

**List of Possible Topics:**

1. **CCHS Translational Research**
   1. Respiratory drive
   2. Cellular mechanisms
   3. PHOX2B
   4. Genetic
   5. Mouse studies
   6. Drug studies
2. **Clinical Management of CCHS**
   1. Non-invasive ventilation
   2. Home mechanical ventilation
   3. Diaphragm pacing
   4. Cardiac management
   5. Endocrine management
   6. GI management
   7. Neurocognitive studies
   8. OB/GYN/Fertility management
3. **CCHS Living Developments**
   1. Developmental strategies
   2. Independent/self-care management
   3. Care-giver approaches
   4. Young adult issues
   5. Relationship issues
   6. Pregnancies topics (IVF, Pre-implantation screening …)

**Submission Guidelines**

Please submit an abstract of the poster presentation. Proposals should include the following components:

* Poster Title
* Author
* Provide a brief biography (150 words) of yourself including your work related to CCHS. Include other author information if appropriate
* Contact information
* Brief abstract of poster, to include
  + Summary of work
  + Intended audience (25-50 words): Describe the level of experience with family populations
  + Presentation outcomes (50 words): Include tangible outcomes that participants will take home from presentation

**Deadline to submit abstracts: January 12, 2018**

**Notification of acceptance: February 16, 2018**

Please go to <http://cchsnetwork.org/2018-conference/proposal-submission/> to complete proposal submission form.

***Thank you for your proposal.***

**Abstract Review Committee:**

***Sheila Kun, RN, BSN, BA, MS, CPN, FCCP, Nurse Care Manager, Pediatric Pulmonology Children's Hospital Los Angeles – Chair***

Dr. Thomas Keens, M.D., Pediatric Pulmonology Children's Hospital Los Angeles

Dr. Ha Trang, M.D.,Ph.D., Diderot University, Paris

Rebecca Martine, MSN, RN, PMHCNS, CCHS Family Network

Kimberly Savino, JD, CCHS Family Network

Ian Hatfield, CCHS Network

Contact Sheila Kun, Abstract Review Committee Chair, at [skun@chla.usc.edu](mailto:skun@chla.usc.edu) for additional information or guidance with abstract submission.

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**July 2018, St. Louis, MO   USA**

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