



2024 CCHS NETWORK FAMILY CONFERENCE

Following numerous cancellations attributed to the COVID-19 pandemic, we are delighted to announce the 2024 CCHS Network Family Conference "Rise & Shine".

Where: Newport Beach, CA

When: June 26 – 28, 2024

Venue: Renaissance Newport Beach Hotel

Go to www.cchsnetwork.org/2024-cchs-family-conference to register.

Go to www.marriott.com/event-reservations/reservation-link.mi?id=1687312780578&key=GRP&app=resvlink to reserve a room at the hotel.

While there is no fee to attend this conference, we kindly request that a donation of \$300.00 be made to the CCHS Network. Go to www.cchsnetwork.org/donate.

This conference will offer much more than an educational agenda. It will celebrate the collective journey that is unique to CCHS families while renewing friendships, celebrating accomplishments and emphasizing the importance of empowerment and advocacy. By blending attendance with clinical specialists and research experts, we anticipate an environment where knowledge is shared, connections are formed and hope is fortified. We will also recognize the significance of 2024 for our rare disease community; marking the 35th anniversary of the CCHS Network, our 9th family conference and our 10th International CCHS Day in September.

We hope to see you there!

PROGRAM

Day/Time	Speaker	Topic
Wednesday, June 26	Registration & Welcome Reception	
1:00 – 3:00p	Registration	
3:00 – 3:30p	Melinda Riccitelli, President, CCHS Network	Welcome
3:30 – 4:10p	Thomas Keens, M.D., Childrens' Hospital of Los Angeles	Keynote Speaker: Tracing the History of Congenital Central Hypoventilation Syndrome
4:15 – 5:00p	CCHS Group Activity: Let the Games Begin	
5:00 – 6:30p	Reception	
Thursday, June 27	CCHS Clinic Pathways: Empowering Health and Wellness	
7:30 – 9:00a	Continental Breakfast	
8:30a – 5:00p	Daycare	
9:00 – 9:40a	Gad Vatine, Ph.D., Ben Gurion University of the Negev	CCHS Research: The Big Picture
9:45 -10:25a	Debra Weese-Mayer, M.D., Lurie Children's Hospital	Patient Registry: The First Step Towards Drug Development
10:25 – 10:45a	Break	
10:45 – 11:25a	Jack Feldman, Ph.D., UCLA	Every Breath You Take
11:30a – 12:10p	Ajay Kasi, M.D., Childrens' Healthcare of Atlanta	Vents, Stomas & Masks Oh My
12:15 – 1:30p	Lunch Sponsored by Avery Biomedical	
1:30 – 2:10p	Iris Perez, M.D., Childrens' Hospital Los Angeles	CCHS Chronicles: More Than Just Breathing
2:15 – 3:05p	James Oakley, CEO, KMB Xenia Proton de la Chapelle, CEO, AtmosR Tony Martins, COO & President, Avery Biomedical	Cutting-edge Technologies and Emerging Treatments
3:05 – 3:15p	Break	
3:15 – 4:45p	Breakout Sessions	
6:00 – 7:30p	Dinner	
Friday, June 28	CCHS Patient Focus: Living Well, Living Strong	
7:30 – 9:00a	Continental Breakfast	
8:30a – 12:30p	Daycare	
9:00 – 9:40a	Maida Chen, M.D., Seattle Childrens' Hospital	CCHS Survival Guide: Adulting Edition – The Fun Facts You Need
9:45 – 10:25a	Liya Rabkina, MS, CGC, Igenomix	Navigating Fertility in CCHS
10:25 – 10:40a	Break	
10:40a – noon	Individual Patient Stories; Patient Panel	
Noon – 12:30p	Closing remarks	

SPEAKER BIOS

Dr. Maida Chen, M.D. is Director of the Pediatric Sleep Center at Seattle Children's Hospital. She is also an Associate Professor in the Department of Pediatrics at the University of Washington School of Medicine. She obtained her medical degree at Northwestern University, did her residency in Pediatrics with DR. Weese-Mayer at Rush-Presbyterian-St. Luke's Medical Center, and then completed a Pediatric Pulmonary Fellowship with a special focus on respiratory control and sleep medicine with Dr. Keens at Children's Hospital Los Angeles. Her clinical practice centers on sleep disorders in infants, children, and adolescents. Her research focuses on respiratory control disorders and sleep-disordered breathing in special needs populations, like CCHS. She is a member of the American Academy of Pediatrics, American Thoracic Society, American Academy of Sleep Medicine and Sleep Research Society. Dr. Chen also serves as a board member on the CCHS Network Research Advisory Board, a panel that reviews CCHS research grant applications for funding.

Jack Feldman, Ph.D. is a renowned breathing researcher at the University of California, Los Angeles (UCLA). With a focus on unraveling the intricacies of respiratory physiology, Dr. Feldman has become a leading figure in the field of breathing science. His significant research contributions include the discovery and exploration of the Pre-Bötzinger Complex, a critical neural center in the brainstem that plays a pivotal role in respiratory rhythm generation. This groundbreaking discovery has provided crucial insights into the neural mechanisms governing breathing patterns and respiratory control. Driven by a profound dedication to respiratory research, Dr. Feldman continues to advance our understanding of the respiratory system, making lasting contributions to scientific knowledge.

Dr. Ajay Kasi, M.D. is a pediatric pulmonologist and assistant professor of pediatrics at Emory University and Children's Healthcare of Atlanta. He completed pediatric residency in Nicklaus Children's Hospital, Miami, FL and pediatric pulmonology fellowship in Children's Hospital Los Angeles. Since starting as a pediatric pulmonologist in Atlanta, Dr. Kasi helped establish the Diaphragm Pacing Program at Children's Healthcare of Atlanta. This unique program is specifically designed for children with CCHS and is one of only a few of its kind offered in the country. His research focuses on ventilatory management strategies in CCHS and cystic fibrosis early lung disease. He has published on clinical aspects of caring for children with CCHS. Dr. Kasi is board certified in pediatrics and pediatric pulmonology and is a member of American Thoracic Society, American Academy of Pediatrics, and American Academy of Sleep Medicine. Dr. Kasi also serves on the CCHS Network Research Advisory Board, a panel that reviews CCHS research grant applications for funding.

Dr. Thomas Keens, M.D. has recently retired after 40 years as a Pediatric Pulmonologist at Children's Hospital Los Angeles (CHLA) and a Professor of Pediatrics at the Keck School of Medicine at the University of Southern California. Dr. Keens is among a handful of experts in the world experienced in treating children with CCHS. He has authored or co-authored well-over 50 articles about CCHS. Dr. Keens research efforts was in the area of Cystic fibrosis (CF), Sudden infant death syndrome (SIDS), CCHS, Pediatric respiratory physiology and home mechanical ventilation. Dr. Keens is Board certified in Pediatrics, Neonatal-Perinatal Medicine, and Pediatric Pulmonology. He is a member of the American Physiological Society; Society for Pediatric Research; American Pediatric Society; American Academy of Pediatrics; American Thoracic Society; American College of Chest Physicians; Sleep Research Society; and the International Society for the Study and Prevention of Infant Deaths. In 2019, Dr. Keens was awarded the most prestigious "Pediatric Founders Award" by the Pediatric Scientific Assembly of the American Thoracic Society for his seminal contributions to the science and practice of pediatric respiratory medicine. Dr. Keens serves as an Advisory Board Member for the CCHS Network One World Registry.

Tony Martins, with over three decades of experience in the field of breathing pacemaker technology, serves as the Chief Operating Officer and President of Avery Biomedical. Mr. Martin's expertise has been instrumental in the development and advancement of the Avery Diaphragm Pacing System, a pioneering solution in the realm of implanted phrenic nerve and diaphragm stimulation. The Avery Diaphragm Pacing System comprises surgically implanted electrodes and receivers, complemented by an external transmitter and antennas. This innovative system offers a transformative approach to addressing respiratory issues, providing patients with enhanced control over their breathing function. With a track record of more than 2,000 successful patient implants, Avery Biomedical has established itself as a beacon of safety and reliability in the medical device industry.

James Oakley, CEO, KeepMeBreathing a lawyer and astute businessman, shares a common bond with the CCHS community as a devoted parent. Inspired by the challenges faced by his son, Casper, who battles with CCHS, Mr. Oakley decided to channel his energy and expertise into making a tangible difference. In response to the critical need for enhanced ventilatory equipment for CCHS patients, James founded a nonprofit technology company, KeepMeBreathing (KMB). Mr. Oakley's dual role as a dedicated parent and visionary entrepreneur showcases the power of personal experiences in driving positive change within the CCHS community and highlights the potential for collaboration between the business world and healthcare to bring about meaningful advancements for those living with rare respiratory conditions.

Iris Perez, M.D. succeeded Dr. Thomas Keens as Director of the Congenital Central Hypoventilation Syndrome and Diaphragm Pacing Program at Children's Hospital Los Angeles. Dr. Perez is recognized for her exceptional care and expertise in managing patients with Congenital Central Hypoventilation Syndrome (CCHS). Dr. Perez's commitment to the well-being of children affected by CCHS is evident in her specialized approach to diagnosis, treatment, and ongoing care for these individuals. Her dedication to advancing both clinical and research aspects of CCHS has positioned her as a leading figure in the field of pediatric pulmonology, making a significant impact on the lives of patients and contributing to the broader understanding of this rare respiratory disorder. Under her leadership, CHLA continues to provide compassionate and cutting-edge care for children with CCHS.

Xenia Proton de la Chapelle, CEO, AtmosR, a BioPharma company, shares a profound connection with the CCHS community as a fellow parent of a child with CCHS. In her dual role as a business leader and dedicated parent, Xenia brings a unique perspective to her work, driven by personal experiences with her child, Joany. Under her leadership, AtmosR focuses on advancing biopharmaceutical solutions in CCHS, with a keen and heartfelt understanding of the pressing needs faced by individuals like Joany. Xenia's commitment to both her professional endeavors and the CCHS community exemplifies the potential for meaningful contributions at the intersection of business and healthcare, with a focus on improving the lives of those affected by rare respiratory conditions.

Liya Rabinka, MS, CGC serves as a genetic counselor at Igenomix, a prominent global biotechnology company with a specialized focus on reproductive genetics and women's health. In her role, Ms. Rabinka plays a pivotal part in the intricate landscape of genetics, particularly concerning molecular genetic conditions, with a commitment to supporting individuals and families through their genetic journeys. Ms. Rabinka guides families in interpreting genetic information, including the molecular aspects of conditions such as Congenital Central Hypoventilation Syndrome (CCHS). As a genetic counselor, she helps individuals understand the implications of genetic testing results, providing them with the knowledge needed to make informed decisions about their reproductive choices.

Dr. Gad Vatine, Ph.D. is a Professor and Researcher in the Physiology and Cell Biology Department and the Regenerative Medicine and Stem Cell (RMSC) Research Center at Ben-Gurion University of the Negev. Dr. Vatine is at the forefront of CCHS cellular and molecular research, and his bioengineered iPSC platforms give real hope in uncovering the intricacies of CCHS. Dr. Vatine received his Ph.D. in 2011 from Tel Aviv University where he studied the mechanisms underlying light-entrainment of the circadian clock using zebrafish as a model. He followed this with a short postdoc at Bar-Ilan University where he established a zebrafish model for the rare psychomotor disability disorder MCT8-deficiency. Next, he joined the laboratory of Dr. Clive Svendsen at the Regenerative Medicine Institute at Cedars-Sinai where he pioneered the concept of disease modeling at blood-brain barrier (BBB) using patient-specific induced pluripotent stem cells (iPSCs). In 2017, he became an assistant professor at The Physiology and Cell Biology Department and the Regenerative Medicine and Stem Cell Research Center at Ben-Gurion University of the Negev. The Vatine lab generates personalized iPSC-based models to study mechanisms underlying various rare neurological disorders, including CCHS, and to test potential treatments in these conditions. He is also the director of the BGU-iPS-core facility. The CCHS Network has wholeheartedly supported the research endeavors led by Dr. Vatine over the past few years, alongside his collaborative efforts with Dr. Ashkenazi.

Debra Weese-Mayer, M.D. is the Beatrice Cummings Mayer Professor in Pediatric Autonomic Medicine at Northwestern University Feinberg School of Medicine and Chief of the first Center for Autonomic Medicine in Pediatrics (CAMP) at Lurie Children's Hospital. Dr. Weese-Mayer is recognized internationally for her clinical and research work in the emerging discipline of pediatric autonomic medicine and is a lead translational researcher at Ann & Robert H. Lurie Children's Hospital and the Stanley Manne Children's Research Institute. Dr. Weese-Mayer's notable work includes her involvement in the discovery and understanding of the PHOX2B gene's role in CCHS. As a key figure in unraveling the genetic underpinnings of this rare disorder, she has played a crucial role in advancing diagnostic and therapeutic approaches for patients with CCHS. She has authored more than 250 peer-reviewed articles, reviews, chapters, and abstracts. Her clinical and research programs have grown to include a wide-ranging referral base (48 states; 50 foreign countries). Dr. Weese-Mayer was awarded the March of Dimes Jonas Salk Health Leadership Award in Research for 2005. Dr. Weese-Mayer is board Certified in Neonatal-Perinatal Medicine and General Pediatrics and is a member of the American Autonomic Society Statement on Autonomic Medicine in Pediatrics, American Thoracic Society, CJ Foundation for SIDS Scientific Advisory Board, RADICA-FRE Scientific Advisory Board, Society for Pediatric Research. Dr. Weese-Mayer's commitment to bridging clinical care with groundbreaking research underscores her dedication to improving the lives of individuals affected by rare respiratory conditions at Lurie Children's Hospital and beyond.