



2021 Annual Report

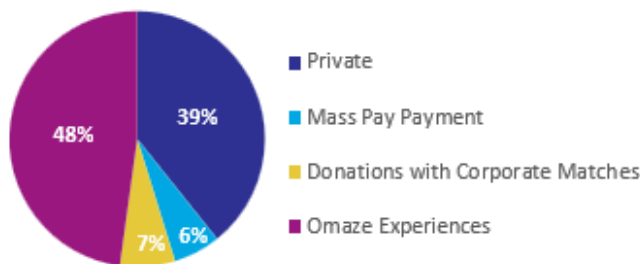
The **CCHS Network** is a 501(c)(3) US-registered charity. Together, we champion scientific advances that will empower individuals living with Congenital Central Hypoventilation Syndrome (CCHS) and their loved ones to live full and productive lives. Our vision is a future where CCHS is no longer a life-threatening diagnosis. Over the past seven years, International CCHS Day has generated a surge of awareness and advocacy for our orphan disease. This year, we are **TURNED THE TIDE** to uncover greater ingenuity, research, and treatment options. We invited our community of families and supporters to help give CCHS its day in the sun on November 13th, 2021. Our efforts were broadened by celebrity champions, including Jonah Hill, Henry Winkler, Charlize Theron, Ariel Winter, and Leighton Meester among others, who lent their voices and social media platforms to our cause. CCHS Day 2021 raised **\$129,000**. When combined with private donor expansion, social media outreach, and personal fundraisers, donations outpaced our annual goal by 26%. We are proud to report a final 2021 revenue of **\$628,696**. The CCHS Foundation sincerely thanks all our **heroes** who made this year one of **merit, validation, and hope**. Your work and devotion are transforming the future of the 1500+ individuals who live each day committed to being **BRAVE, RESILIENT, and DETERMINED!**

OUR MISSION

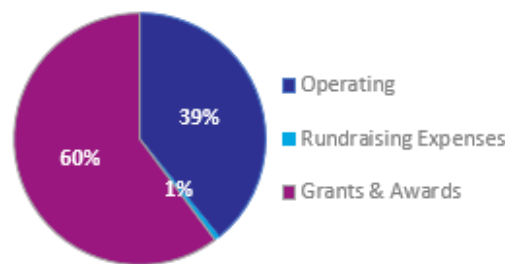
The aim of the Foundation is to raise money to **support CCHS research** (75% commitment), **continue CCHS educational outreach** (20% commitment), and **assist CCHS patients and families through the Ellen Whisman Fund** (5% commitment). To this end, we value integrity, transparency, accountability, collaboration, leadership, sensitivity, optimism, philanthropy, proactivity, and volunteerism.

THE INS & OUTS

Raised Funds - \$628,696



Expenditures - \$151,498



COLLABORATIONS

In 2021 the CCHS Foundation continued to partner with **OMAZE**, a fundraising platform, to raise funds for CCHS causes. Omaze works in conjunction with **Charities Aid Foundation America**, a US-registered, 501(c)(3) public charity. Through the generous work of Omaze and CA America, the CCHS Foundation was gifted \$300,669 in 2021.

Michael Hess, American Entrepreneur and Businessman, gifted the CCHS Foundation with a one-time gift of \$50,000 after seeing CCHS patients in social media posts. We continued **commercial giving partnerships** in 2021 with Amazon Smile, Good Shop, PayPal Charitable Giving Fund, and Network for Good. We also maintained corporate match program relationships with enhanced donations from Blackrock, Enterprise Holdings, Hewlett-Packard, Parallon, State Farm, Duke Energy Foundation, and HCA Caring Foundation.

At the heart of our organization is the tireless efforts of determined CCHS families. We want to thank all our donors, large and small, for making 2021 so successful. Some noteworthy contributions came from **Susan and Gerry Ballard** who gave **\$14,000** in personal donations and **\$5000** in matching contributions. **John Trevisan, John Martine, and [] and [] Thomas** again made generous donations totaling \$30,000 in 2021.

Finally, the Foundation also continued to build **collaborative relationships** with the European Network for Central Hypoventilation Syndromes as well as CCHS organizations in Brazil, Denmark, France, Germany, Japan, Israel, Mexico, Italy, Poland, and Spain.

MOVING MOUNTAINS

The CCHS Foundation continued to sponsor three innovative CCHS research projects. **Drs. Gad Vatine, Ph.D.** (Ben-Gurion University, Israel) and **Avraham Ashkenazi, Ph.D.** (Tel Aviv University, Israel) were granted \$400,000, over a 2-year period, to study degradation pathways of misfolded PHOX2b in specific CCHS derived iPSCs. **Drs. Douglas A Bayliss, Ph.D.** and **Yingtang Shi, M.D.** (University of Virginia, United States) received \$75,000 to continue to scrutinize the molecular mechanisms of brainstem respiratory drive. **Dr. Jorge Gallego, Ph.D.** (Inserm research Director at Robert Debré Hospital, Université de Paris) was awarded \$50,000 to investigate pharmacological treatments that may counteract CCHS impairment, and putatively improve respiratory function. The CCHS Foundation also maintained the provision of the **CCHS NOW Registry**, a natural history study of CCHS that aims to fill research gaps.



INTERNATIONAL CCHS DAY

The CCHS Foundation proudly sponsored the **7th Annual International CCHS Day** titled **"Turning The Tide"** on **November 13, 2021**. When energy is needed at a sporting event, fans will often start "the wave". It soon travels around the stadium, unifying a group of people with a shared mission. We asked our community to do a collective wave from around the globe to support CCHS this year. A total of **\$129,000** was raised for CCHS Day 2021.



ON THE HORIZON

2022 CCHS Grant Award Funding Decision

September 30, 2022

8th Annual International CCHS Day

November 13, 2022