



The CCHS Foundation

2020 Annual Report

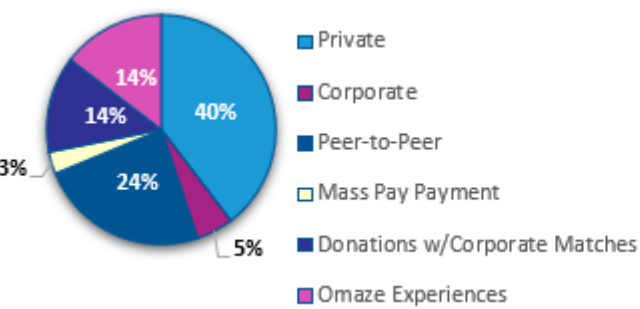
The **CCHS Foundation** is a division of the **CCHS Network**, a 501(c)(3) charity. Together, we champion scientific advances that will empower individuals living with Congenital Central Hypoventilation Syndrome (CCHS) and their loved ones to live full and productive lives. Our vision is a future where CCHS is no longer a life-threatening diagnosis. Although the COVID19 pandemic made 2020 a trying year, our global community rose to the challenge and produced our most successful fundraising campaign to date. The **6TH Annual International CCHS Day** was centered around the recognition of everyday CCHS heroes. 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 2020 raised **\$179,467**. When combined with private donor expansion, social media outreach, and personal fundraisers, profits outpaced our annual goal by nearly 30%. We are proud to report a final 2020 revenue of **\$360,283**. 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

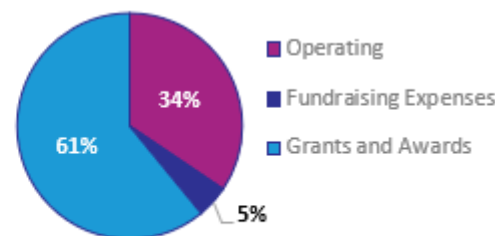
The aim of the Foundation is to raise money to **support CCHS research** (75% commitment), **continue CCHS educational outreach** (20% commitment), and **assist CCHS patients and families through the Ellen Whisman Fund** (5% commitment). To this end, we value integrity, transparency, accountability,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

THE INS & OUTS

Raised Funds - \$339,516



Expenditures - \$44,244



COLLABORATIONS

In 2020, the CCHS Foundation formed an important partnership with **OMAZE**, a fundraising platform that “gives everyone a chance to dream big and win once-in-a-lifetime prizes while helping to make the world a better place”. 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 \$52,985 in 2020.

The CCHS Foundation also collaborated with celebrity **Jessica Barden** on a successful t-shirt campaign that brought in \$20,000. **Commercial giving partners** in 2020 included Amazon Smile, Good Shop, PayPal Charitable Giving Fund, and Network for Good. We also continued to grow our corporate match program 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. **Laura Brown** and **Randi Watkins** demonstrated this critical resolve, having collectively raised over \$11,000 through individual community fundraisers.

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.

SOCIAL OUTREACH

4300 Facebook Followers

3900 Instagram Followers

418 Twitter Followers



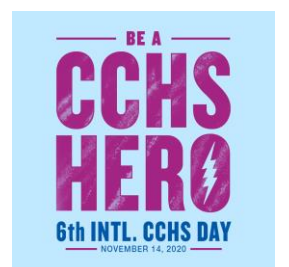
Daily social media posts encouraged global awareness, education, advocacy and giving. In 2020, the Foundation saw an approximate **65% expansion of social media followers**.

MOVING MOUNTAINS

The CCHS Foundation continued to sponsor innovative CCHS research and community-building conferences. Although the grant award cycle was suspended due to COVID19, 2020 saw the fruition of previously funded research projects by **Douglas A Bayliss, Ph.D.** (University of Virginia, United States), **Drs. Ha Trang, M.D., Ph.D.** (Hôpital Robert Debré, France), and **Brigitte Piallat, Ph.D.** (Genoble Institute, France), and **Drs. Gad Vatine, Ph.D.** (Ben-Gurion University, Israel) and **Avraham Ashkenazi, Ph.D.** (Tel Aviv University, Israel). Dr. Bayliss’ work was featured in both *Cell Reports* and *Nature* and Drs. Vatine and Ashkenazi published their results in *Stem Cell Research*. 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 **6th Annual International CCHS Day** titled **Be A CCHS Hero** on **November 14, 2020**. We saw the nomination of nurses, grandparents, siblings, and other influential people who lighten the burden of life with CCHS. Supporters also suited up in personalized t-shirts and participated in our Virtual Walk/Run Challenge. Additional fundraisers included t-shirt sales, marathon fundraisers, peer-to-peer efforts, and individual Facebook fundraising campaigns. A total of **\$179,467** was raised through CCHS Day 2020.



ON THE HORIZON

2021 CCHS Grant Award Funding Decision
September 17, 2021

6th Annual International CCHS Day
November 13, 2020