



The CCHS Foundation

2019 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. In its fifth year of existence, the CCHS Foundation continued to evolve both in effort and impact, with a focus on **community involvement**, **international advocacy**, and **corporate outreach**. The **5th Annual International CCHS Day** alone raised **\$232,158.34**, a 67% increase from 2018. The resounding success of CCHS Day 2019 was bolstered by celebrity activists Jonah Hill and Henry Winkler, who appeared in a public service announcement launched on CCHS Day. The video garnered **over 32,000 views**. When combined with private donor expansion, social media campaigns, and personal fundraisers, the Foundation easily surpassed its \$150k annual goal, **raising over \$339k**. From these efforts, **three innovative research projects** were funded. The CCHS Foundation sincerely thanks all our supporters who made this year one of **merit, validation, and hope**. Your work and devotion is transforming the future of the 1200+ individuals who live each day being **BRAVE, RESILIENT, and DETERMINED**.

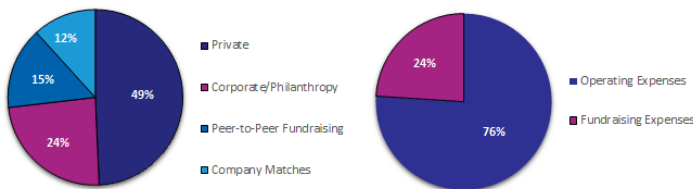
OUR MISSION

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.

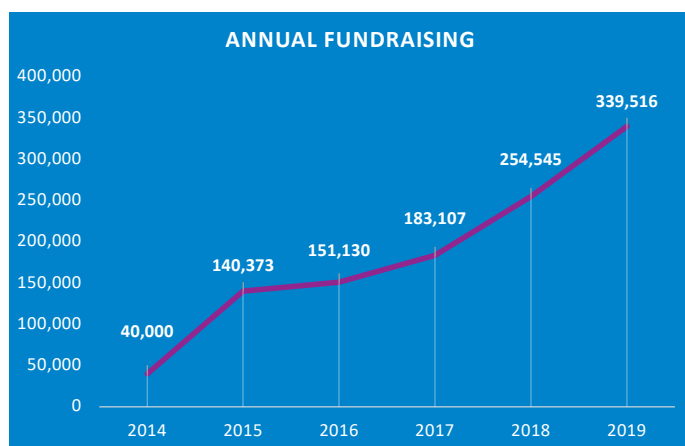
THE INS & OUTS

Raised Funds - \$339,516

Expenditures - \$44,244



CELEBRATING FIVE YEARS OF SUCCESS



The Foundation reported a **compounded annual growth rate of 53.4%** since its conception in 2014.

SOCIAL OUTREACH

4033 Facebook Followers

849 Instagram Followers

332 Twitter Followers



Daily social media posts encouraged global awareness, education, advocacy and giving. In 2019, the Foundation saw an approximate **17% expansion of social media followers** across the three platforms.

MOVING MOUNTAINS

Through the remarkable fundraising efforts of the CCHS community in 2019, the CCHS Foundation supported **three groundbreaking research projects during this funding cycle**. Grants were awarded to **Dr. Douglas A Bayliss, Ph.D.** (University of Virginia, United States), **Drs. Ha Trang, M.D., Ph.D.** (Hôpital Robert Debré, France) and **Brigitte Pierrat, 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' project aims to better understand loss of respiratory drive action in CCHS. Drs. Trang and Pierrat are analyzing deep brain stimulation as a possible treatment option for CCHS. Drs. Vatine and Ashkenazi are studying the removal of misfolded proteins in CCHS.

INTERNATIONAL CCHS DAY

The CCHS Foundation proudly sponsored the **5th Annual International CCHS Day** titled ***It only Takes a Second*** on **November 9, 2019**. CCHS families, supporters and celebrities from around the world participated in this event by promoting a PSA video featuring Jonah Hill and Henry Winkler. Additional events included dine and donates, t-shirt sales, a gala, individual Facebook fundraising campaigns, and a high school fundraiser. A total of **\$232,158.34** was raised through these collective efforts.



ON THE HORIZON

6th Annual International CCHS Day
November 14, 2020