



The CCHS Foundation

2016 Annual Report

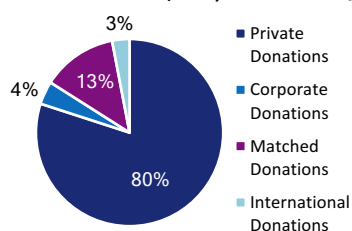
Two thousand and sixteen marked continual growth for the CCHS Foundation and demonstrated the power of **community, commitment, and industry**. The CCHS community once again responded to a call for action through international fundraising, social media campaigns, donor expansion, and corporate partnerships. The **2nd Annual International CCHS Day**, held on November 12, 2016, was another resounding success and allowed us to meet our yearly fundraising goal. From these efforts, two research projects were initiated in 2016, expanding our knowledge of respiratory control and gene function in CCHS. Our research vision continues with the awarding of two new translational projects in 2017. Furthermore, the CCHS Network research stance was endorsed by the National Organization of Rare Disorders (NORD) with a partnership grant to conduct a longitudinal natural history study of CCHS. The CCHS Foundation **sincerely thanks all of our supporters** who made this year one of **merit, validation, and hope**. Your work and devotion is transforming the future of 1200+ individuals who live each day being **BRAVE, RESILIENT, and DETERMINED**.

OUR MISSION

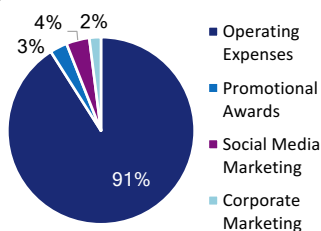
The aim of the Foundation is to raise money to **support CCHS research** (70% commitment), **continue CCHS educational outreach** (20% commitment), and **assist CCHS patients and families through the Ellen Whisman Fund** (10% commitment). To this end, we value integrity, transparency, accountability, collaboration, leadership, sensitivity, optimism, philanthropy, proactivity, and volunteerism.

THE INS & OUTS

Raised Funds - \$151,130.06



Operations - \$13,552.88



NETWORKING

The CCHS Foundation worked diligently to secure and expand relationships with leaders in the rare disease community, specifically the **National Organization for Rare Disorders (NORD)**. The CCHS Family Network was awarded a NORD grant in April 2016 to conduct a five year **National History Study on CCHS. Rare Disease Day** was honored on February 29, 2016 and a **webinar** was co-sponsored with **Global Genes** on October 18, 2016. Additional partners included **Avery Biomedical, Amazon Smile, Bravelets, and Good Shop**. The Foundation continued to collaborate with the **European Network for Central Hypoventilation Syndromes** as well as CCHS organizations in **Japan, Israel, Mexico, Italy, and Poland**.

ON THE HORIZON

2017 Research Award Announcement
June 2017

3rd Annual International CCHS Day
November 11, 2017

CCHS Family Network Conference & International Research Conference
June 2018



SOCIAL OUTREACH

3175 Facebook Followers

The Foundation intensified its social media presence with daily posts across **Facebook, Instagram** and **Twitter** in an effort to raise global awareness and advocacy. Additionally, the CCHS Family Network and CCHS Foundation revamped the existing website to include modern resources for families and professionals.



MOVING MOUNTAINS

Through the remarkable fundraising efforts of the CCHS community in 2015, the CCHS Family Network was able to fund **two groundbreaking research projects** in 2016. Grants were awarded to Dr. Doug Bayliss, University of Virginia, and Dr. Isabella Ceccherini, UOC Medical Genetics Institute. Both studies aim to better understand the inner workings of the Phox2B gene with the intention of uncovering **viable drug interventions** for CCHS.

INTERNATIONAL CCHS DAY

The CCHS Foundation proudly sponsored the **2nd International CCHS Day** named **Light Up The Night For CCHS** on **November 12, 2016**. CCHS families and supporters from around the world participated by "lighting up the night" and sharing pictures on a Facebook event page.



Grassroots events included dine and donates, a quilt raffle, a jewelry fundraiser, a high school field hockey fundraiser, and a comedy night. Approximately twenty CCHS families matched monies raised by the larger community, donating a minimum of \$1000 each. An online store was established for the sale of CCHS Day t-shirts. A total of **\$120K was raised** through these collective efforts.

HASHTAGS OF HOPE

#OURCURSEISOURCAUSE
#CCHSDAY2016
#RAREDISEASEDAY
#LIGHTUPTHENIGHT