



The CCHS Foundation

2017 Annual Report

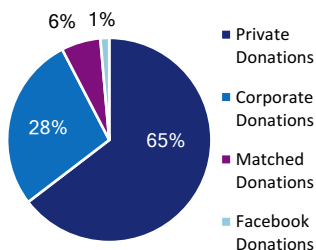
In its third year of existence, the CCHS Foundation continued to evolve both in effort and impact. While continuing to focus on **community involvement** and **international advocacy**, the Foundation's mission was extended to **corporate outreach**. The Foundation proudly welcomed **Avery Biomedical** and **Bayada Home Health Care** as its **first corporate sponsors**. Grassroots initiatives fortified the success found in 2017. The **3rd Annual International CCHS Day** raised over **\$109k**. When combined with **private donor expansion**, **social media campaigns**, and a **read-a thon**, the Foundation easily surpassed its \$150k annual goal, **raising over \$183k**. From these efforts, **two research projects** were funded and monies were earmarked for the upcoming **2018 International CCHS Research Conference** in St. Louis, Missouri. 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 1200+ individuals who live each day being **BRAVE, RESILIENT, and DETERMINED**.

OUR MISSION

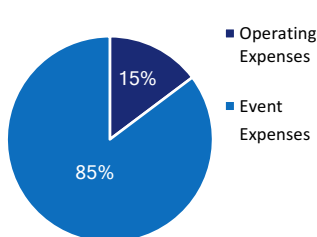
The **CCHS Foundation** is a division of the **CCHS Network, Inc.**, a 501(c)(3) charity. Together, we champion scientific advances that will empower individuals living with CCHS and their loved ones to live full and productive lives. Our vision is a future where CCHS is no longer a life-threatening diagnosis. 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 - \$183,107



Operations - \$13,307



COLLABORATIONS

The CCHS Foundation was adopted by two corporate sponsors in 2017, **Avery Biomedical** and **Bayada Home Health Care**. Each of these companies committed \$25k to furthering the Foundation mission. Additionally, the Foundation worked diligently to secure and expand relationships with leaders in the rare disease community, specifically the **National Organization for Rare Disorders (NORD)**. Additional partners included **Amazon Smile**, **Bravelets**, **Global Genes**, **Good Shop**, and **Network for Good**. We also continued to grow our Corporate Match program with matching donations from **Blackrock**, **Enterprise Holdings**, **Hewlett-Packard**, **Prudential Insurance**, and **State Farm**. 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**.

SOCIAL OUTREACH

3537 Facebook Followers

The Foundation delivered a strong social media presence with daily posts across **Facebook**, **Instagram** and **Twitter** in an effort to raise global awareness and advocacy.



MOVING MOUNTAINS

Through the remarkable fundraising efforts of the CCHS community in 2016, the CCHS Foundation secured funding for **two groundbreaking research projects** in 2017. Grants were awarded to Dr. Namasivayam Ambalavanan at the University of Alabama and Dr. Diego Fornasari at the University of Milan, Italy. These studies aim to better understand the cellular mechanisms of action of the Phox2B gene with the intention of developing **viable drug interventions** for CCHS.

INTERNATIONAL CCHS DAY

The CCHS Foundation proudly sponsored the **3rd Annual International CCHS Day** titled **Dance 'Til Dawn For CCHS** on **November 11, 2017**.

CCHS families and supporters from around the world participated by posting videos of their friends and family dancing in support of CCHS to a dedicated Facebook event page. Additional fundraisers included dine and donates, t-shirt sales, a gala, individual Facebook fundraising campaigns, and a high school field hockey fundraiser. A total of **\$109K was raised** through these collective efforts.



ON THE HORIZON

2018 Research Award Announcement
June 2018

International CCHS Conference
June 2018

4th Annual International CCHS Day
November 10, 2018

