



The CCHS Foundation

2018 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 fourth 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 **4th Annual International CCHS Day** raised **\$138,703.70**, a 27% increase from 2017. When combined with private door expansion, social media campaigns, and the Arch of Hope fundraiser, the Foundation easily surpassed its \$150k annual goal, **raising over \$257k**. From these efforts, **two research projects** will be funded. In addition, monies raised sponsored the **5th International CCHS Research Conference** at the Chase Park Plaza Hotel in St. Louis, MO, June 20 – 23, 2018. The conference provided a platform for advancing research efforts, boosting education, and fostering collaboration between scientists, clinicians, and patients. 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**.

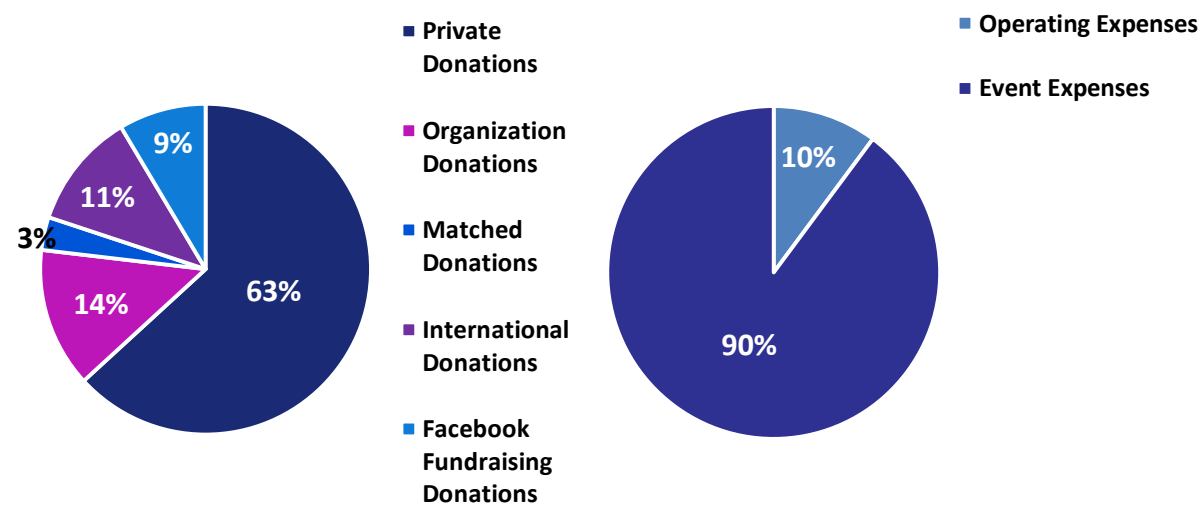
OUR MISSION

The 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 Foundation Board voted to modify the 2018 distribution procedure, granting a higher percentage of funding to research.*

THE INS & OUTS

Raised Funds - \$257,589.65 Expenditures - \$16,272.59



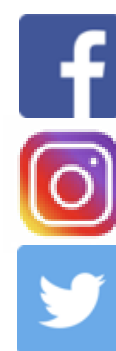
COLLABORATIONS

The CCHS Foundation added the **Ruby Dooby Foundation**, **John A. Trevisan Charitable Fund**, and **Thomas Family Gift Fund** to their list of philanthropic sponsors in 2018. 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)** and **Global Genes**. Commercial giving partners included **Amazon Smile**, **Bravelets**, **Good Shop**, **PayPal Charitable Giving Fund**, and **Network for Good**. We also continued to grow our Corporate Match program with matching donations from **Blackrock**, **Enterprise Holdings**, **Hewlett-Packard**, **Parallon**, and **State Farm**. The Foundation continued to collaborate 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

3811 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.

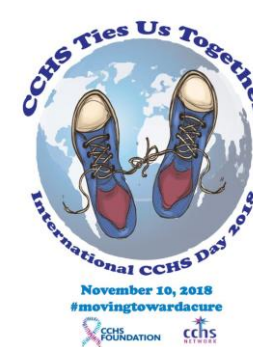


MOVING MOUNTAINS

Through the remarkable fundraising efforts of the CCHS community in 2017, the CCHS Foundation secured funding for **two groundbreaking research projects in 2018**. Grants were awarded to **Dr. Patrice Guyenet, Ph.D.** at the University of Virginia and **Dr. Raffaele Piumelli, M.D.** at the Meyer Children Hospital, Florence, Italy. **Dr. Guyenet's** project aims to better understand the regulation of breathing when asleep and awake. **Dr. Piumelli** is examining the effects of oxidative stress in CCHS patients.

INTERNATIONAL CCHS DAY

The CCHS Foundation proudly sponsored the **4th Annual International CCHS Day** titled **CCHS Ties Us Together** on **November 10, 2018**. CCHS families and supporters from around the world participated by posting videos of friends and family "tied together" in support of CCHS on a dedicated Facebook event page. Additional fundraisers included dine and donates, t-shirt sales, a gala, individual Facebook fundraising campaigns, and a high school fundraiser. A total of **\$138,703.70 was raised** through these collective efforts.



ON THE HORIZON

2019 Research Award Announcement
September 1, 2019

5th Annual International CCHS Day
November 9, 2019

