

2024 ANNUAL REPORT

The CCHS Network is a 501(c)(3) US-registered charity. We have a multi-focused mission that ensures the education and support of patients with congenital central hypoventilation syndrome (CCHS) and their families, facilitates inter-family and family-clinician communication, and encourages the acceleration of CCHS research. Our vision is a future where CCHS is no longer a life-threatening diagnosis. The work of our organization centers on integrity, transparency, accountability, collaboration, leadership, sensitivity, optimism, philanthropy, proactivity, and volunteerism.

Building Community, Empowering Patients, Championing Research

SUMMARY

When combined with donor expansion efforts, social media outreach, investments, and personal fundraisers, we are proud to report income of \$394,822.

ON THE HORIZON

Rare Disease Day 2025

Quality of Life Collaborative Research Project Publication, Early 2025

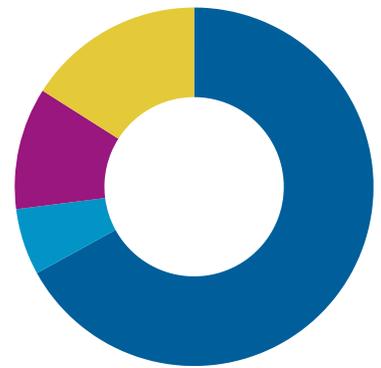
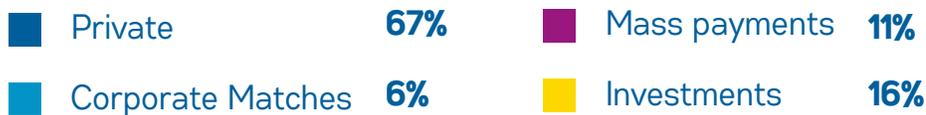
CCHS Leadership Meeting: March, 2025. Paris

11th International CCHS Day: September 27, 2025

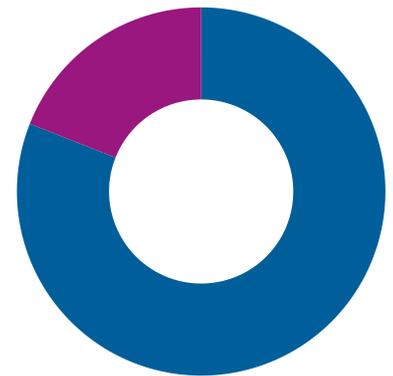
FINANCIAL SUMMARY

The CCHS Network dedicates financial donations to advancing research, supporting educational outreach, and providing direct assistance to patients and families. By funding scientific studies, the Network fosters critical discoveries that improve care and deepen understanding of CCHS. Educational efforts raise awareness among healthcare professionals and the public, while family support programs offer resources, guidance, and community for those living with the condition. Over the last decade, our community's generosity has made a powerful impact - \$3,000,000+ raised through fundraising efforts, all because of donors who believe in family, progress, research, and hope.

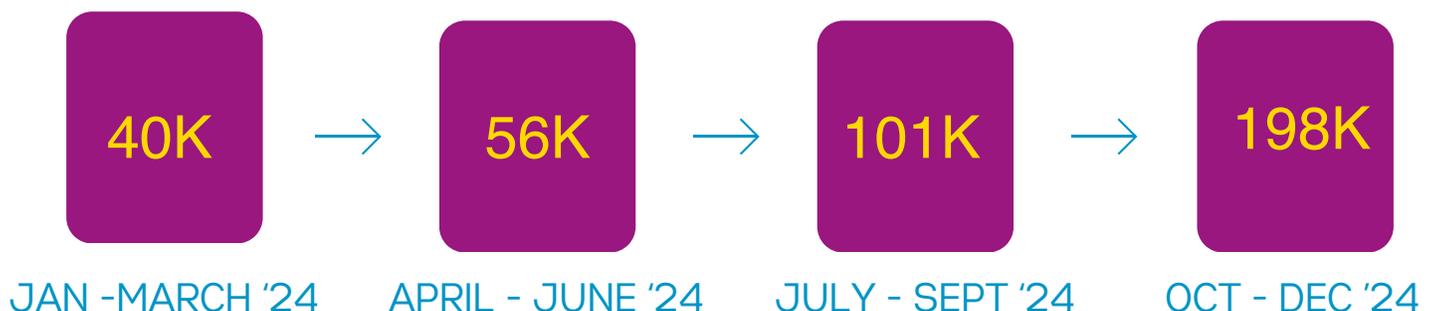
INCOME - \$394,822.



EXPENDITURES - \$436,811



REVENUE GROWTH PER QUARTER



IMPACT SUMMARY

EDUCATION & ADVOCACY

As a rare disease nonprofit, the CCHS Network stands as a bridge between science and family, offering not only vital information and support, but also a sense of belonging in what can otherwise feel like an isolating diagnosis. We pledge an unwavering commitment to walking alongside families – every step of the way – while advocating for progress, connection, and hope in the face of a lifelong, complex condition.

For Rare Disease Day this year, the Schueler family went above and beyond to raise awareness for CCHS. They lit up the Big Four Bridge in Louisville, Kentucky, in the vibrant colors of the CCHS Network, creating a striking visual reminder of the rare condition that affects so many families. In addition, Ryan Schueler walked the entire bridge throughout the night to raise both funds and awareness in honor of his daughter, Greta, who lives with CCHS. Their dedication not only highlighted the challenges faced by those with CCHS but also inspired the local community and the broader CCHS Network, showing the power of advocacy, family, and determination.

Bill Hatfield was at it again for CCHS in 2024! Bill had already hiked the Appalachian Trail (a whopping 2200 miles) and the Colorado Trail (500 miles) to raise awareness and funds for CCHS. This year he took on kayaking the Erie Canal (338 miles) to raise awareness and funds for CCHS.

In June of this year we hosted another CCHS Family Conference in Newport Beach, California. The CCHS Conference brought together patients, families, and caregivers from around the world for a meaningful and inspiring gathering. From listening to CCHS speakers such as Tom Keens, Debbie Weese-Mayer, Maida Chen, Iris Perez, Ajay Kasi, Gad Vatine, Jack Feldman, and other talk about CCHS to embracing the heartfelt lived experiences shared by CCHS patients, the conference was inspiring and meaningful. And though the event was rich in many experiences, *the most lasting impact was the new friendships that will continue far beyond the conference.*



IMPACT SUMMARY (CONT.)

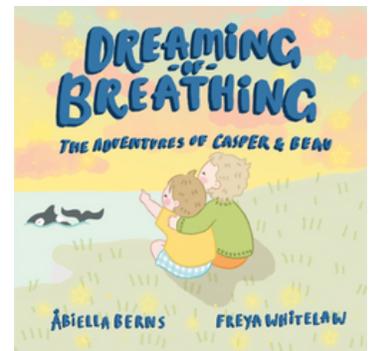
INTERNATIONAL CCHS DAY 2025

The CCHS Network's primary initiative for advocacy and fundraising is International CCHS Day. This year marked our tenth annual day of awareness and giving with the theme of "Rise and Shine". For 2024 International CCHS Day, the CCHS Network partnered with Keep Me Breathing to promote the children's book *Dreaming About Breathing*. This enchanting story follows two friends, Casper and Beau who share the same rare breathing condition. Each night, as they connect to their ventilators, Casper and Beau meet in their dreams to embark on magical adventures - diving for treasure and even riding a whale! Through this partnership, we raised awareness of CCHS in a child-friendly way, celebrated the courage of young patients, and provided a fun, relatable story for families navigating life with CCHS. To cap off this year's CCHS Day we had a virtual talent show that highlighted the talents of our amazing patient population.

International CCHS Day 2024 raised a total of \$75,425 thanks to the efforts of our determined CCHS community, global supporters and donors, and celebrity champions.

GLOBAL COLLABORATIONS

In addition to International CCHS Day, **2024** underscored the vital role of international collaboration in advancing our understanding of and response to CCHS. Throughout 2024, the CCHS Network, in collaboration with AtmosR and led by Xenia Proton de la Chapelle, spearheaded a global initiative to better understand the impact of CCHS on the quality of life of both patients and their caregivers. This important project brought together international perspectives, data, and experiences to highlight the daily challenges, successes, and needs of the CCHS community. The findings will help guide future programs, research priorities, and resources aimed at improving support and outcomes for families affected by CCHS.



RESEARCH

The CCHS Network research grant program plays a vital role in advancing scientific understanding and medical care for individuals with Congenital Central Hypoventilation Syndrome (CCHS). By funding innovative research projects, the program fosters collaboration among scientists, clinicians, and families, accelerating discoveries that can lead to improved diagnostics, treatments, and quality of life for those affected by CCHS. It is a key driver of hope and progress within the global CCHS community.

In 2024, the CCHS Network funded two meritorious research grants. Dr. Peng Li, University of Michigan, was awarded \$75,000 to uncover how NTS Phox2b neurons work and how they receive signals to control breathing. Their findings could lead to better understanding and new treatments for CCHS and related breathing disorders. Drs. Hernandez-Miranda and Strauss were awarded \$75,000 to study dB2 neurons - why are they unique, how do they work within the breathing control system, and how do PHOX2B and LBX1 genes influence their development and function.



2024 AT A GLANCE

