2023 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

CCHS Day 2023 raised $136,995. When combined with donor expansion efforts, social media outreach, investments, and personal fundraisers, we are proud to report income of $398,524.

ON THE HORIZON

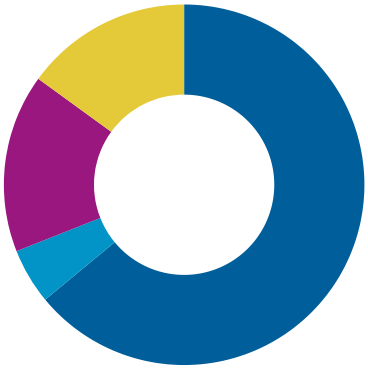
Rare Disease Day 2024
CCHS Network Family Conference: Rise and Shine, June 26-28, 2024, Newport Beach, CA
International CCHS Day: September 2024

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.

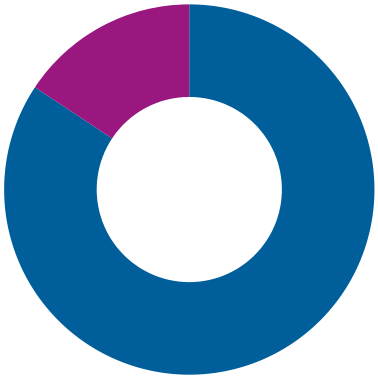
INCOME - $398,524.

- Private **64%**
- Mass payments **16%**
- Corporate Matches **5%**
- Investments **15%**



EXPENDITURES - $450,636

- Programs **82%**
- Operations **16%**



REVENUE GROWTH PER QUARTER

55K → 93K → 205K → 398K

JAN -MARCH '23 | APRIL - JUNE '23 | JULY - SEPT '23 | OCT - DEC '23

IMPACT SUMMARY

EDUCATON & 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. The Network is deeply committed to raising awareness and understanding of CCHS through modern, accessible tools like webinars, social media, and community-driven campaigns. Our private Facebook page has become a lifeline – a compassionate, international support group where CCHS patients and families connect, share, and find strength in one another. We're often the first place newly diagnosed families turn to for guidance, as well as a source of support for those awaiting genetic confirmation of the PHOX2B mutation. We strive to maintain open and ongoing communication with both families and the multidisciplinary clinicians who care for them. Through our quarterly newsletters, we keep our community informed, connected, and empowered with the latest CCHS news and resources. 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.

The CCHS Network's primary initiative for education and advocacy is International CCHS Day. This year marked our ninth annual day of awareness and giving with the theme of "This Little Light of Mine". CCHS Day 2023 raised a total of $136,995 thanks to the efforts of our determined CCHS community, global supporters and donors, and celebrity champions.

GLOBAL COLLABORATIONS

In addition to International CCHS Day, **2023** underscored the vital role of international collaboration in advancing our understanding of and response to CCHS. One of the most significant moments came in September, when members of the global CCHS community gathered in Orlando, Florida, for a landmark event that highlighted cutting-edge research and fostered meaningful dialogue. Researchers, clinicians, and CCHS leaders from across the world came together to share their latest findings, exchange insights, and strengthen partnerships. This gathering served not only as a platform for scientific advancement but also as a powerful reminder that progress in rare disease research is most effective when driven by a united, global effort.

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 2023, the CCHS Network funded two meritorious research grants. Drs. Daniel Mulkey and Cleyton Sobrino, University of Connecticut, were awarded $75,000 to study the role of PHOX2B-expressing nucleus tractus solitarius (NTS) neurons in breathing and survival in mice with CCHS. These neurons serve as a primary pathway for controlling breathing based on oxygen levels, which can help maintain breathing when CO2 drive is compromised. Dr. Javier Oroz Garde was awarded $75,000. His group researches the structure of the mutated PHOX2B protein with the hope of outlining the step-by-step process that causes PHOX2B to become toxic.

2023 AT A GLANCE

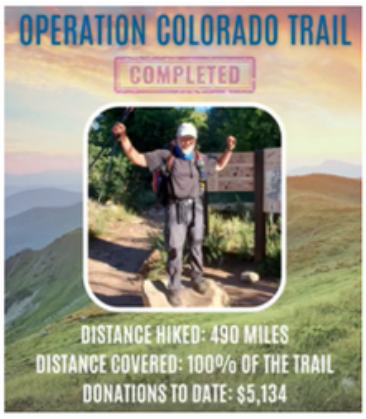
TODAY ALL OUR LITTLE LIGHTS SHINE BRIGHT FOR CCHS

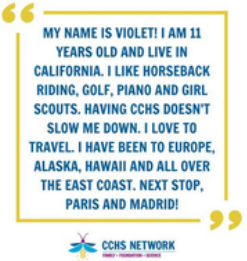
CCHS Day 2023 is... TOMORROW

Fundraising Spotlight

On August 30, Bill Hatfield completed his 490-mile hike across the Colorado Trail. He traveled from Denver to Durango and raised over $5k for the CCHS Network. A huge congratulations and tremendous amount of gratitude to Bill and all those who supported his journey!

#castalightoncchs #cchsnetwork





MY LITTLE LIGHT SHINES FOR CCHS
www.cchsnetwork.org