

2022 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.

SUMMARY

CCHS Day 2022 raised \$176,618. When combined with donor expansion efforts, social media outreach, and personal fundraisers, we are proud to report a total profit of \$363,312.

ON THE HORIZON

International CCHS Research Conference: Orlando, FL, September 2023

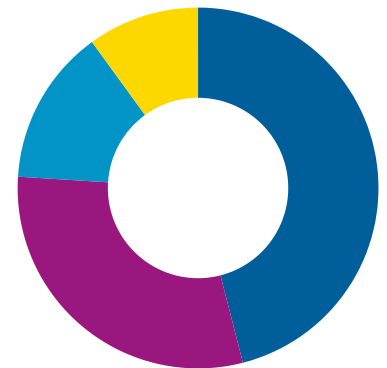
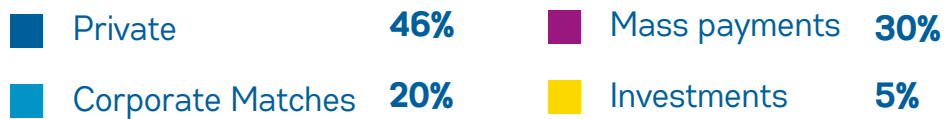
Rare Disease Day 2023

International CCHS Day: September 2023

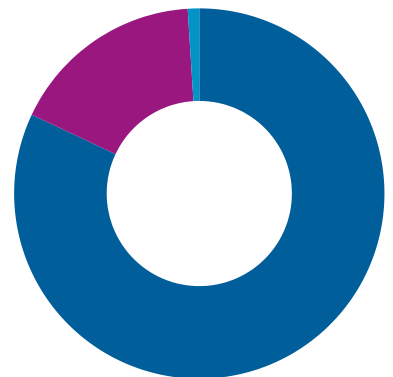
FINANCIAL SUMMARY

The CCHS Network dedicates 75% of all financial donations to research funding, 25% to educational efforts and 5% to patients and families in need via the Ellen Whisman Fund.

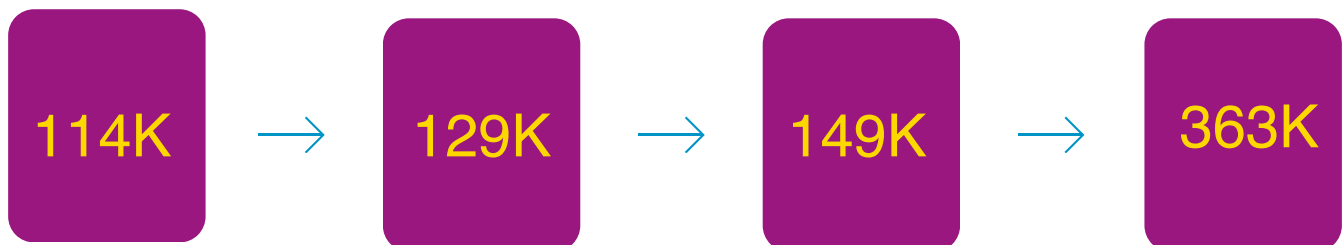
INCOME - \$363,312



EXPENDITURES - \$228,919



REVENUE GROWTH PER QUARTER



JAN -MARCH '22

APRIL - JUNE '22

JULY - SEPT '22

OCT - DEC '22

IMPACT SUMMARY

EDUCATION & ADVOCACY

The CCHS Network aims to modernize CCHS recognition and education through webinars, social media marketing and community based campaigns. Our private Facebook page serves as the only known “support group” for CCHS patients and families with international participation. Additionally, the Network serves as a first line resource for newly diagnosed families as well as families waiting for genetic confirmation of the Phox2B mutation. We strive to maintain open and consistent lines of communication with patients and families as well as multidisciplinary clinicians caring for our rare disease community. The CCHS Network distributes electronic newsletters nearly monthly to share important CCHS updates with the community.

The CCHS Network’s primary initiative for education and advocacy is International CCHS Day. This year marked our seventh annual day of awareness and giving with the theme of “SHINING A LIGHT” on CCHS. This focus aligned with the CCHS Network’s rebranding process from June through July 2022 that established the firefly as our official organizational logo. CCHS Day 2022 raised a total of \$176,618 thanks to the efforts of our determined CCHS community, global supporters and donors, and celebrity champions, including Jonah Hill, Henry Winkler, Charlize Theron, Ariel Winter, and Leighton Meester.

RESEARCH

In 2022, the CCHS Network enhanced our commitment to the funding of meritorious research with our largest grant to date. Drs. Gad Vatine, Ph.D. (Ben-Gurion University, Israel), and Avraham Ashkenazi, Ph.D. (Tel Aviv University, Israel), are currently in the second year of their \$400,000, two-year grant to investigate the degradation pathways of misfolded PHOX2b in specific CCHS-derived iPSCs.

Concurrently, Drs. Douglas A Bayliss, Ph.D., and Yingtang Shi, M.D. (University of Virginia, United States) were awarded \$75,000 to further scrutinize the molecular mechanisms of brainstem respiratory drive. Additionally, Dr. Diego Fornasari, Ph.D. (Associate Professor of Pharmacology Department of Medical Biotechnology and Translational Medicine) received \$75,000 to explore the role of a recently identified regulatory non-coding RNA (PHOX2B-AS1) in CCHS pathogenesis and assess its potential as a therapeutic target. The CCHS Network also continued to support the CCHS NOW Registry, a natural history study aiming to address research gaps in CCHS.

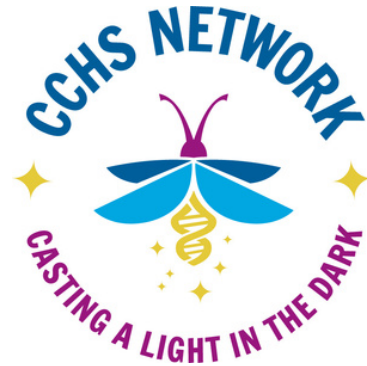
Our dual focus on research and patient support underscores the network's pivotal role in fostering community engagement, championing scientific advancements and opening avenues for therapeutic interventions in the CCHS rare disease community.

2022 AT A GLANCE



CCHS NETWORK

FAMILY • FOUNDATION • SCIENCE



A BREATH OF FRESH AIR

OUR NEW LOOK

In anticipation of International CCHS Day 2022, we are delighted to share our organization's new image. After working with a graphic design team for several months, the Network Board chose the firefly to represent our small but active CCHS community. Its symbolism touches on the power of a bright light shining through the dark as well as our unique practice of glowing through the night.



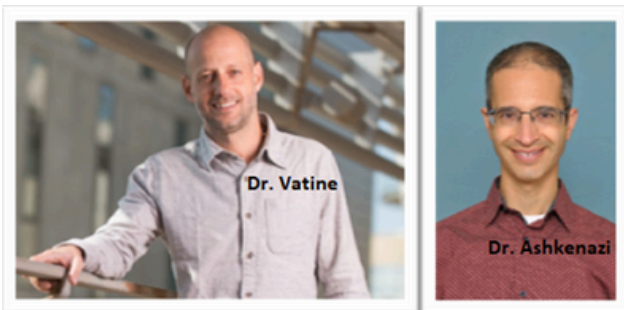
I'm casting a light on one of the rarest disorders in the world.

Congenital Central Hypoventilation Syndrome (CCHS)

Imagine needing a ventilator to survive a nap on the couch. Imagine having to depend on a machine to keep your child alive every time they close their eyes. Imagine having a medical condition in the twenty-first century without one available drug. Help me spark **HOPE** for this orphan disease by donating to their parent-run 501(c)(3) organization, the **CCHS Network**. All proceeds go to advancing treatments, accelerating research and assisting for families in need.

#cchsday2022 #castalightoncchs

@cchsnetwork | www.cchsnetwork.org

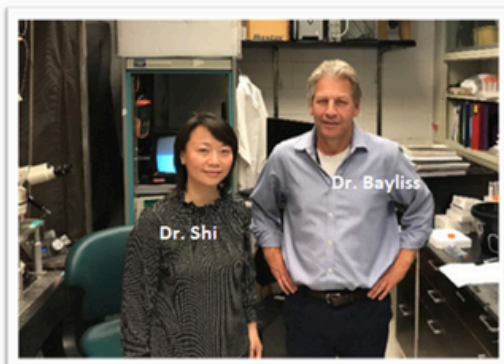


Dr. Vatine

Dr. Ashkenazi

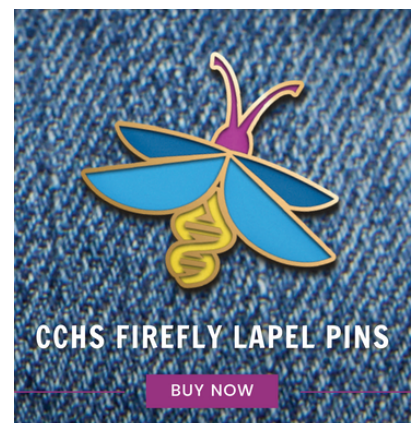


Dr. Fornasari



Dr. Shi

Dr. Bayliss



CCHS FIREFLY LAPEL PINS

BUY NOW