



CCHS NETWORK

FAMILY • FOUNDATION • SCIENCE

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CCHS NETWORK

Position: Executive Director

Status: Full Time. Exempt

Reports To: President, Board of Directors

ABOUT CCHS NETWORK:

The CCHS Network, Inc. is a 501(c)(3) organization founded in 1989 to raise awareness of Congenital Central Hypoventilation Syndrome (CCHS). CCHS is a rare complex genetic disorder, usually diagnosed at birth, which affects the automatic nervous system's ability to automatically and spontaneously breathe during sleep, along with many other multi-system complications. To learn more about the organization, please visit www.cchsnetwork.org

THE OPPORTUNITY:

The CCHS Network was founded in 1989 from a deep need: to connect families whose lives had been forever changed by the rare disease diagnosis, CCHS, and who, at the time, had nowhere to turn. Scattered across the country, these pioneering families came together to create a community rooted in support, shared knowledge, and hope. That small group became the foundation of something extraordinary - the CCHS Network! As word spread about the Network's invaluable support and trusted information, more families joined. Today, the community has grown to include ~ 1200 families worldwide - proof of the power of connection and shared purpose.

Over the years, the CCHS Network has grown into a powerful force - not only supporting families but also becoming a driving light in raising awareness about this complex and still incurable condition throughout the medical and scientific communities, both here in the U.S. and around the world. What began as a lifeline for families has grown into a transformative catalyst for change, sparking progress, connection, and hope like never before. The Network now champions innovative, high-impact research, having awarded more than \$2M in funding over the past two decades. With a strong foundation and a clear vision for the future, the CCHS Network is poised to deepen its impact - bringing progress, knowledge, and hope to the CCHS community around the globe.

Over the past 30+ years, the CCHS Network has grown steadily thanks to the dedication of a volunteer Board of Directors, who have also served as the organization's working staff. This model has sustained the Network through decades of impact but with the increasing volume of responsibilities and growing scope of its work, the organization has reached a pivotal moment. To build on this momentum and bring its strategic vision to life, the CCHS Network is now seeking to hire its first Executive Director - an essential milestone in the organization's continued growth and impact. This leader will work closely with the Board to strengthen the organization's capacity, expand its reach, increase its fundraising and deepen its impact across the CCHS community.

ABOUT THE POSITION:

The Executive Director is responsible for the overall leadership and management of the organization representing 1200+ patients and families. Reporting directly to the Board of Directors this role will drive strategic initiatives, oversee financial stewardship and serve as the face of our organization. The successful candidate will be a dynamic advocate with a proven track record in nonprofit leadership, fundraising and community engagement, combined with a passion for addressing the unique challenges faced by the CCHS community. The Executive Director will bring compassion and empathy to the role and, if not already familiar with CCHS, will develop a deep understanding of the Syndrome to effectively engage with the CCHS community at all levels and broaden awareness beyond it. Responsibilities include developing and executing a multi-faceted fundraising plan, implementing and refining the 2025-2027 strategic plan, overseeing the organization's budget, and managing daily operations. This position will play a key role in advancing both the short- and long-term strategic and fundraising goals of the organization. Working in close partnership with the Board of Directors and its committees, the Executive Director will help raise public awareness of the disease and of the CCHS Network, expand programs that support the CCHS community, and communicate the organization's value and ongoing contributions to families, researchers, and medical professionals. This position is remote with one in-person Board meeting yearly.

The Executive Director will work closely with the Board President to develop meeting agendas, coordinate meeting dates/times, communicate effectively with the Board, and provide, in a timely and accurate manner, all information necessary for the board to function properly and make informed decisions.

EXECUTIVE DIRECTOR COMPETENCIES:

The Board seeks candidates with the following competencies:

- **Collaborative Leadership.** The ED will be a warm and engaging leader who is accessible and listens to all viewpoints, demonstrates confidence, and has a positive approach. The ED must

be a highly accomplished relationship builder, comfortable in developing strategy and achieving buy-in from the Board and others and disciplined in executing plans and encouraging accountability. The ED, with Network leaders, will promote the compelling vision, mission, values, and strategic goals of CCHS Network to the varied CCHS communities. The ED must see the big picture - managing current issues while thinking long term. The ED will be decisive in action, self-directed, adaptable, humble, independent thinker, confident, and accountable.

- **Ability in Fundraising and Resource Development.** The ED must identify, engage, and steward donors and seek contributions of significance from various sources. Innovative and attuned to donor interests and concerns, the ED will inspire fundraising involvement from the Board and will guide them about “best practices” in donor development. He/she will also cultivate additional/alternative revenue streams to enhance and improve the organization’s funding potential. The ED will reach out and cultivate new potential donors/funding sources at all levels and work closely with the Board and others, for example, families, medical community, private foundation contacts, philanthropists, to generate funding opportunities. As well as overseeing the development of communications materials for diverse populations within the CCHS community (e.g. families, donors, professionals, and partners), and working remotely with a volunteer Board of Directors who live across the country.

- **Expertise in Communication.** The ED is principally responsible for supporting and nurturing various communications by coordinating messages and internal and external outreach with the Board President and Executive Board. His/her communication and behavioral style should earn the Board’s trust, respect, and support and align with the organization’s culture and values.

- **Fiscal Management.** The ED must plan for financial stability and sustainability in partnership with the Board Finance Committee and Treasurer. A key to this is having knowledge about organizational finances, the ability to establish and oversee a realistic budget, and the aptitude to use timely financial statements to guide and oversee organizational performance.

- **Marketing and Presentation.** The ED, together with the Board’s Marketing Committee, will work to build the visibility and credibility of the Network through strategic communications and the development of new opportunities to showcase CCHS Network’s growth, track record, and ability to build partnerships. Raising the profile of CCHS Network throughout the community, especially among funding sources and influencers, is paramount.

- **Sound Interpersonal Skills Management.** The ED will support a culture of inclusion, opportunity, and accountability in the environment. He/she will foster innovation, teamwork, and collaboration to ensure that goals are established, resources appropriately allocated, and results achieved.

KEY RESPONSIBILITIES/ESSENTIAL FUNCTIONS

The key accountabilities and responsibilities of this position include, but are not limited to:

- **Resource Development.** As the 'fundraiser in chief,' the ED is charged to drive results in fundraising by:
 - Helping identify, cultivate and solicit prospective donors including high net worth individuals, private foundations, and institutional funding sources.
 - Leveraging personal and professional contacts and relationships of the Board and supporters into transformational fundraising opportunities.
 - Having a strong background with grant writing and reporting, creating individual, foundation, and sponsorship packets, and building membership programs.
 - Exploring alternative/earned revenue streams.
 - Forecasting revenue/contributions and expense budgets - able to build Proformas.
 - Promoting an optimistic culture of growth and engagement in the organization, at both at the Board and (future) staff level.
- **Strategic Management.** The ED serves as the principal resource to the Board and offers his/her advice about the strategic plan and decisions based on his/her experiences and proven track record.
 - Expected to have a visionary mindset needed to move the organization forward, finetune the organization's strategies and work plans, as well as assign responsibilities and accountabilities.
 - Coordinates work associated with the strategic plan, tactics, and opportunities.
 - Continually assesses results/impact and keeps the board informed when shifts in the guiding strategy cause a need for re-evaluation.
- **Organization and Operational Management.** The ED needs to have strong people and project management skills because he/she will help build a high performing board, engage with outside advisors/contractors, and hire future staff.
 - She/he will play a lead role in vetting, engaging, and mentoring new talent to serve initially on Board Committees, Task Forces, and/or Advisory Boards.
 - Develop and adapt the annual plan and budget as a roadmap and tool for accountability.

- Establish effective decision-making processes and Standard Operating Procedures (SOP) to encourage efficient use of resources (people, time, and money) and enable successful growth.
- Ensure effective systems for program evaluation and regularly assess the program portfolio, ever mindful of the need to adapt to the needs of various communities.
- Build and cultivate a partnership with the Board of Directors, providing them with the information and ‘best practice’ training necessary to fulfill their governance duties and to become organizational ambassadors.

QUALIFICATIONS:

The ideal candidate will have:

- Passion for and commitment to CCHS Network’s unique mission and the ability to inspire others to partner in support of that mission.
- Knowledge of the rare disease communities.
- Established connections with donors.
- A proven track record in successfully leading and growing revenue and generating transformational support in non-profit organizations.
- A proven record of financial oversight, budgeting, and basic nonprofit financial management.
- A proven record of and genuine interest in successfully building trusted relationships with and among diverse constituencies and stakeholders.
- A successful track record of working with a board of directors, managing volunteers, and understanding the patient advocacy world.
- Comfortable with technology tools (CRM systems, donor databases, virtual collaboration tools, websites, social media, etc.).
- Soft skill business competencies include sense of urgency, adaptability, intrinsically self-directed, and self-motivated.
- Strong written and oral communications skills.
- Comfortable and adept working with 100% remote teams and sharing and editing materials thorough Google docs or other content/management platforms.

- A minimum of a bachelor's degree with 5+ years with management and governance experience in the public, private, or non-profit sector.

EQUAL EMPLOYMENT OPPORTUNITY (EEO):

CCHS Network values a diverse workplace and strongly encourages women, people of color, LGBTQ+ individuals, people with disabilities, members of ethnic minorities, foreign-born residents, and veterans to apply. The CCHS Network is an equal opportunity employer. Applicants will not be discriminated against because of race, color, creed, sex, sexual orientation, gender identity or expression, age, religion, national origin, citizenship status, disability, ancestry, marital status, veteran status, medical condition, or any protected category prohibited by local, state, or federal laws.

TO APPLY:

To apply, submit a resume and cover letter electronically to jobs.cchsnetwork@gmail.com with "ED Application_Your Name" in the email's subject line. In your cover letter please include examples of fundraising with revenue results, management, nonprofit, advocacy, and virtual work experiences. Resumes without a cover letter will not be reviewed.

SALARY RANGE:

Compensation is competitive and includes opportunities for growth based on the success of fundraising efforts. Benefits offered.