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CYSTIC FIBROSIS
FOUNDATION®

COMMUNITY CHIEF OPERATING OFFICER

ABOUT CYSTIC FIBROSIS FOUNDATION

The mission of the Cystic Fibrosis Foundation is to cure cystic fibrosis and to provide all people with cystic fibrosis the opportunity to lead long, fulfilling lives by funding research and drug development, partnering with the CF community, and advancing high-quality, specialized care.

The Cystic Fibrosis Foundation is an organization like no other. For more than five decades, the CF Foundation has led the way in advancing the development of transformative treatments for cystic fibrosis and fostering dramatic improvements in CF care, while laying the groundwork to find a cure for cystic fibrosis.

A nonprofit, donor-supported organization, the CF Foundation is the world's leader in the search for a cure for CF, a life-threatening genetic disease that primarily affects the lungs and digestive system. Historically, cystic fibrosis was considered a children's disease with a low survival rate to adulthood. Today, thanks to the research and therapies that the CF Foundation has developed with its partners, there are more adults living with cystic fibrosis than children.

Established in 1955 by parents and families of people with CF, the CF Foundation supports a nationwide network of 114 care centers and best-in class research centers, its own fifty-person basic research lab, and 52 chapters across the U.S. that strive to fund and support the mission. The CF Foundation is widely recognized for pioneering the venture philanthropy model – leveraging its scientific and clinical expertise to fund ground-breaking research with biotechnology and pharmaceutical companies, as well as academic medical centers, in its pursuit of novel treatments and a cure for CF.

Key Facts

- 685 total staff
- $400M annual budget
- $606M annual revenue; $5.4B endowment
- CFF by the Numbers
- 2020 Annual Report
- Path to a Cure

Mission

We will not rest until we find a cure for all people with cystic fibrosis.

Vision

Cure **F**ound

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Along the way, the CF Foundation has become one of the leading healthcare nonprofits in the United States. Nearly every CF drug and therapy available today was made possible because of CF Foundation support. The CF Foundation did this not only for the 30,000 people living in the U.S. with CF – and the estimated 70,000 people worldwide – but for the families who have worked tirelessly to find a cure for their loved ones living with the disease. While leading transformation of CF therapy and care, the CF Foundation has also built an extraordinarily interconnected community of CF patients, families, volunteers, donors, caregivers, and researchers strongly devoted to a shared mission. This deeply engaged community is supported by a national network of CF Foundation chapters, and dedicated advocacy and community partnership teams.

The pathbreaking progress the CF Foundation has achieved depends in part on the dedication and unwavering commitment of a talented team of CF Foundation employees. The Foundation has created a culture that attracts – and retains – a diverse group of talented people who are passionate about changing the face of cystic fibrosis.

CORE VALUES

The CF Foundation is guided by a set of core values that permeates its work at all levels:

- Keep sight of **what really matters**: Make every decision based on what is best for people with cystic fibrosis and their families.
- **Aspire for excellence** in all we do: Take pride in our work. Commit to continuous learning and improvement.
- Stronger **together**: Collaborate and work together so that we can learn more and achieve more.
- **Innovate** with courage: Embrace challenges. Reach beyond boundaries in pursuit of our vision.
- Care about **our people**: Care deeply about our staff and all those who support our shared mission. Listen with respect. Support one another.

CFF VENTURE PHILANTHROPY MODEL

In the last 30 years, research funded by the CF Foundation has helped to increase the median predicted survival or people living with cystic fibrosis from 29 years to 50 years.

Through an innovative venture philanthropy model, the Cystic Fibrosis Foundation provides early-stage funding to scientists and pharmaceutical companies to develop breakthrough treatments for people diagnosed with CF. As an "orphan disease" (one affecting fewer than 200,000 people), there was historically very little interest in developing treatments for the underlying causes of CF until the Foundation stepped in to offer direct funding. This was a revolutionary step, as disease-focused voluntary health organizations had not previously partnered with for-profit drug companies in this way.

In January 2012, the U.S. Food and Drug Administration approved the first drug to treat the underlying causes of cystic fibrosis, vastly improving the day-to-day lives of thousands of people living with CF. Two years later, the CF Foundation sold its royalty rights to the treatments developed through that initial

partnership for nearly $3.3 billion and is using the funds to accelerate the development of new treatments, advance high-quality care, and help people with CF and their families get the tools and support they need, and to pursue a lifelong cure for the disease. The venture philanthropy model has been widely praised and has even been adopted by the National Institutes for Health and other nonprofits as a strategy to quickly and more effectively develop treatments for rare diseases.

As a result of these innovations in treatment, as well as work to implement best practices in care centers treating CF across the country, support to people living with CF and their families, and ongoing advocacy work, the CF Foundation is at the epicenter of fighting cystic fibrosis in the U.S. and abroad. Research that is funded by the CF Foundation has also given hope to others suffering from other orphan diseases and the research the CF Foundation funds to address infections has the potential to help millions of people worldwide, not just those with CF.

The Cystic Fibrosis Foundation is headquartered in Bethesda, MD, with a Therapeutics Lab in Lexington, MA, and 52 chapters across 69 offices throughout the United States.

THE POSITION

The Community Chief Operating Officer, a new position reporting directly to the CEO, will be a key member of the CF Foundation's senior leadership team, bringing seasoned management experience, a commitment to innovation, and a critical community-driven perspective to the CF Foundation's work. The Community Chief Operating Officer will oversee the operations of the Foundation's national network of chapters and field offices and more than 350 staff. Additionally, the Community Chief Operating Officer will serve as strategic leader of national and local efforts and programs dedicated to engaging and serving people with CF, their families, donors, and volunteers, and partner with fundraising staff to develop and continuously improve the Foundation's fundraising strategy. This position will develop a comprehensive strategy to direct teams across the U.S. in building strong relationships with the diverse and evolving CF community. Direct reports include the Vice President, Field Management and Volunteer & Donor Relations; Vice President, Community Partnerships; and Chief Development Officer.

MAJOR OBJECTIVES

The Community Chief Operating Officer will accomplish the following in the first 12 to 18 months in the position:

- Develop and implement a strategy that aligns Field operations and Development into a cohesive team working toward a shared goal; support the ongoing realignment of chapters and development teams.
- Assess existing programs and initiatives to determine strengths and opportunities and develop a plan for community engagement and service which includes community members as essential partners in our mission.

- Assess and develop plan to optimize community data assets.
- Develop processes, structure, and best practices to integrate community programs and fundraising with the network of accredited care centers in a mutually supportive relationship.
- Use the CF Foundation's commitment to diversity and inclusion to supporting staff in the development of programs to reach all aspects of the CF Community and engage diverse voices to gather feedback and insight across the community.

RESPONSIBILITIES

The Community Chief Operating Officer of the Cystic Fibrosis Foundation will have the following responsibilities:

- **Leadership and Business and People Management:** Set strategic vision for all community programs and initiatives, manage over 350 staff, and oversee 52 local chapters to strengthen community engagement and fuel the mission. Partner with the CEO, executive team, other community-focused departments, CF care centers, the national Board of Trustees, and chapter boards and volunteers to align efforts, maximize reach, and promote operational effectiveness. Be a strong and inspirational presence for chapter staff.
- **Programming:** Help develop and deliver innovative programming that builds connections with and supports people with CF and their families by integrating efforts across Foundation national programs, local chapters, and CF accredited care centers. Develop trusted partnership with the CF community by ensuring that strategies pursued by the CF Foundation are informed and shaped by a diverse representation of people with CF.
- **Fundraising:** Oversee all fundraising, steering the development of innovative strategies to optimize revenue generation. Serve as a point of contact to steward major donors and corporate supporters.
- **Engagement:** Strengthen the approach to engaging volunteers and community members across all programs and ensure a personalized experience that best leverages individual interests and talents to advance the Foundation's mission. Serve as a thought leader for program staff, sharing effective strategies, methodologies, and best practices in authentic and meaningful community engagement.
- **Telling the CF Foundation Story:** Serve as key spokesperson for the Foundation, effectively communicating the Foundation's mission, vision, core values and strategic direction externally to a wide variety of stakeholders.
- **Reach:** Support efforts to expand the reach of the CF Foundation to listen, connect, and serve underserved and under-connected members of the CF community and to unite the CF community by building a welcoming and inclusive experience. Expand community reach through the development of strategic organizational collaborations.



QUALIFICATIONS

The Community Chief Operating Officer will bring the following qualifications:

- Strong track record of general management, with preference for a network organization. Thorough understanding of core business skills, including strategic planning, strategic communications, financial management, human resources, and information systems.
- Experience as a member of a senior leadership team, helping to guide the direction across an organization and interacting with a board of directors at an executive level.
- Superior relationship builder. Strong interpersonal skills and ability to interact with a wide variety of people both internally and externally.
- Team-centric leadership style. Track record of working effectively in a highly cross-functional environment.
- Experience in developing the strategy and large-scale implementation for community programs. Demonstrated commitment to soliciting stakeholder feedback and process improvement.
- Experience in community building, outreach, community relations, and capacity building.
- Experience leading diverse teams. Proven people manager with dedication to professional development and mentorship.
- Excellent oral & written communication skills. Strong presentation skills with the ability to present complex issues with clarity to inspire, motivate, and spur action.
- Strategic thinker. Excellent problem solving skills and ability to anticipate issues and plan an effective response at an organizational and individual level.
- Minimum of fifteen years of relevant professional experience. Work experience in a non-profit setting highly preferred, but not required. Connection to CF a plus.
- Bachelor’s degree required. Advanced degree in a relevant field such as Business Administration or Nonprofit Management strongly preferred.
- Ability to travel 25 percent of the time to provide onsite leadership at community events and for multi-state chapters and field offices.

COMPENSATION AND BENEFITS

The Cystic Fibrosis Foundation is offering competitive compensation for this position. Benefits include medical, dental, and vision insurance; flexible spending account; life and disability benefits; employee assistance program; 401(k) plan with employer match; paid parental leave; and paid vacation, sick, and personal time.

APPLICATION

The Cystic Fibrosis Foundation has retained Campbell & Company to conduct this search. The team for this project includes Marian DeBerry and Colleen Rogers. To be considered for this opportunity, please send a letter of interest and resume to:

COLLEEN ROGERS

Senior Consultant, Executive Search
colleen.rogers@campbellcompany.com
(312) 896-8906 direct

The Cystic Fibrosis Foundation is an equal opportunity employer committed to a diverse workforce. All qualified applicants are encouraged to apply for an open position regardless of race, color, religion, sex, age, national origin, sexual orientation, qualified disability, marital status, and other legally protected statuses.

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