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Executive Search Consultants

DIRECTOR OF DEVELOPMENT THE CHOLANGIOCARCINOMA FOUNDATION THE ORGANIZATION, MISSION AND OPPORTUNITY

The Cholangiocarcinoma Foundation (CCF)'s mission is to find a cure and improve the quality of life for those affected by cholangiocarcinoma (CCA). Founded in 2006, in Salt Lake City, UT, by a family member who lost a loved one to cholangiocarcinoma, CCF has grown to become the leading international resource for research, education, and public awareness about the disease.

Cholangiocarcinoma (CCA) – also known as bile duct or biliary cancer -- is one of the most deadly cancers, with a median life expectancy after diagnosis of 9-12 months. CCA is a silent killer because its signs and symptoms most often remain unnoticed until the cancer is in the advanced stage.

The disease is rare -- about 10,000 people in the United States develop bile duct cancer each year – but devastating to the patients and families it touches. CCA exists in three main forms: perihilar and distal cholangiocarcinoma (outside the liver – sometimes referred to as bile duct cancer), and intrahepatic (within the liver). The 5-year survival rates, according to the American Cancer Society, are stark and unacceptably low, ranging from 30% at best to 2%, depending on the location and stage of the cancer at diagnosis.

CCF began as an online patient discussion board to provide basic information about the disease for newly-diagnosed patients, a service that did not exist in 2006. Patient and caregiver advocacy, support and education remain an essential part of the services the Foundation provides. CCF provides direct support services to patients and caregivers. The robust discussion board on the cholangiocarcinoma.org website has received over 100,000 posts to date on topics ranging from clinical trials to grief support and more. Patient advocacy representatives are available in English and Spanish to assist individuals in locating financial resources, nearby medical centers, and information regarding symptoms, diagnosis and treatment. CCF has published a 136-page book “100 Questions and Answers About Biliary Cancer” and offers a tri-fold brochure in four languages, English, Spanish, Japanese and Chinese.

Increasingly over the past 10 years, the Foundation's focus has gravitated toward the funding and stimulation of cutting edge clinical and basic scientific research. Because CCA is a rare cancer, there is limited incentive for funders to support research. Hence the Foundation's increasingly active role in research.

The Foundation board has recently endorsed a strategic plan that calls for a significant increase in the Foundation's funding capacity, by embracing a \$25 million campaign to support a range of clinical and basic science research initiatives, capacity building and program expansion. This comes on the heels of several years of network building with major research institutions throughout the world, and which has resulted in several important initiatives.

- Initiated in 2012, the International Hepatobiliary Neoplasia Biorepository (IHNB) is a global collaboration between CCF, Mayo Clinic, and multiple academic and medical centers to accelerate research for early diagnosis, novel therapeutics, personalized oncology, and improved clinical outcomes for patients with cholangiocarcinoma. The IHNB has assembled one of the largest bio-specimen repositories for biliary cancers worldwide and serves as a key resource for basic, translational and clinical research in bile duct cancer.

- In 2014, CCF launched the International Cholangiocarcinoma Patient Registry (ICPR) to collect CCA patient information about the incidence and prevalence of CCA and related disorders.
- In 2015, CCF formed a global consortium of research groups, the International Cholangiocarcinoma Research Network (ICRN), that are working in concert to improve knowledge about cholangiocarcinoma etiology, prevention, early detection, treatment and prognosis with an expectation to accelerate scientific and medical progress on an international level, expedite delivery of innovative care and treatments, and improve health outcomes for patients affected by cholangiocarcinoma.
- CCF's Research Fellowship Program was established in 2015 with the goal to raise awareness about cholangiocarcinoma and inspire innovative, quality research. To date, \$1.9 million has been awarded to provide critical seed funding for dozens of physician-scientists at the beginning of their careers. In addition, CCF has also funded four distinguished Conquer Cancer Young Investigator Awards, one resulting in a publication in *Nature Magazine*.
- Each year, CCF hosts an Annual Conference. In 2019, nearly 500 attendees from 40 states, and 18 countries represented academia, healthcare, industry, patient advocacy organizations, patients, caregivers and supporters shared best practices, discussed cutting-edge research findings, expanded current partnerships across and within institutions, and forged new alliances throughout the entire cholangiocarcinoma community.

The Cholangiocarcinoma Foundation is proud to be a partner in coordinating the first World Cholangiocarcinoma Day, held on February 17, 2016. In 2017, CCF served as the lead organizer of this global collaborative initiative to create awareness of both symptoms and treatments. As a 501(c)(3) public charity, with a Platinum GuideStar rating, over \$2.4 million has been raised from donations since the organization's founding. CCF is virtually based, with no physical office space, and staff, board and advisors reside throughout the United States and beyond. The organization currently receives nearly 500,000 hits on its website annually and has more than 12,000 followers on Facebook. More than 100 webinars and videos have been posted on the CCF YouTube and Vimeo channels.

Overview of the Position:

The selected candidate will have opportunities to substantially enhance and sustain the Foundation's revenue stream and create the programs and initiatives necessary to implement the Strategic Plan. The overall goal is to raise \$5 million a year during the five years of the plan. He or she will collaborate with the CCF CEO, Board of Directors and Executive Director in the creation of a comprehensive development operation to support the organization's mission and strategic direction. We are looking for candidates with a proven track record of raising funds nationally and internationally for healthcare and/or related organizations. The selected candidate will promote the work of CCF and educate thought leaders and potential donors who can personally assist in supporting the mission or connect the organization to those who can.

Duties and Responsibilities

- Lead the effort to create a vital and effective professional development operation.
- Work with the Founder/CEO & Board to develop a multi-year plan for achieving the 5-million-dollar annual development goals and establish a master calendar that outlines all fund-raising events and campaigns.
- Plan, manage and implement a major gifts and annual giving program that includes individual, corporate and foundation support.

- Build and lead a sophisticated development operation which includes identifying the need for additional staff and resources to create a state-of-the-art development operation.
- Collaborate with the Board and other supporters to develop relationships with individuals, foundations and corporate sponsors who can support the mission and build a pipeline of donors for CCF.
- Assist the Board in identifying potential board members and onboarding new members as they become involved in the organization.
- Cultivate new leads, research and prepare strategies and solicit gifts of \$10,000 or more from individuals, foundations and corporate organizations. Serve as the relationship manager for a portfolio of prospects and donor relationships. Involve staff and board at appropriate times to assist in presentations.
- Support the staff preparing grant proposals so that communications reflect the most up-to-date information on CCF activities and research. Coordinate the grant reporting process with staff to insure accuracy and timely reporting.
- Manage and establish goals for staff coordinating development operations including prospect research, donor and gift management, communications and stewardship.
- Maintain accurate records, contact reports, updates on visits and communications and report regularly to the Chief Executive Officer and the Board of Directors.
- Coordinate efforts within the organization to assure effective donor stewardship with the goal of generating multi-year giving at various fundraising levels.
- In the first 6 months, strengthen the annual fund, major gifts and planned giving initiatives to meet the goals of the Strategic Plan.
- Evaluate and assess the over 9,000 current donors and determine the best approach to continually involve them in their support of the organization at appropriate levels.
- Lead, monitor, evaluate and document development activities to ensure a return on investment.
- Assure that best practices are in place and that relevant and innovative fundraising messages are developed for diverse demographic and geographic supporter

Candidate Qualifications

- Self-starter with an entrepreneurial spirit and proven ability to establish and maintain relationships with major gift prospects.
- Documented history of closing gifts in excess of \$10,000 plus with successful track record of coordinating and/or soliciting gifts at the \$100,000 plus level with national and international donors.
- Passion for raising funds for healthcare and research.
- Proven achievements with annual fund, major gifts and planned giving.
- Collaborator who is comfortable assisting others to take the lead or can take the lead when necessary.
- Ability to set priorities and execute plans effectively.
- Compelling and engaging interpersonal, written and verbal communications skills.
- Flexibility in dealing with a wide variety of people combined with the ability to process information and accurately share it with colleagues
- Minimum Bachelor's degree combined with 7-10 years of experience in major gift fundraising and management of development professionals.
- Experience in global fund development is preferred.
- Creative, problem solver who can work independently and be self-motivated.
- Have a valid passport and the flexibility to travel nationally and internationally.



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- **Compensation:** Competitive Compensation
- **Location:** The Foundation is operated as a virtual organization. Therefore, residency in Salt Lake City, UT is not a condition of employment. The selected candidate will be required to travel to Utah for meetings and throughout the U.S. and abroad as part of his or her role as chief fundraiser.

All qualified candidates will receive consideration for employment without regard to race, color, religion, sex, national origin, disability, veteran status, or any other characteristic protected by law

**H C SMITH LTD – CHOLANGIOCARCINOMA FOUNDATION
DIRECTOR OF DEVELOPMENT**

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