

# I. CHESTER COUNTY COMMUNITY FOUNDATION GRANT PROPOSAL SUMMARY SHEET

**One page only.** This page will be shared electronically with Grant Committee Members & Fund Advisors.

Note: If Philanthropy Network of Greater Philadelphia's Common Grant Application is used, the Community Foundation's Summary Sheet **MUST** accompany application.

To obtain an electronic version of this application, visit [www.chescocf.org](http://www.chescocf.org)

**Date 12/3/19**

**Contact Information**

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FEIN: 13-6193105	

Has your nonprofit ever applied to the Community Foundation? Yes \_\_\_ No X Not Sure \_\_\_  
 Has your nonprofit ever received funding from the Community Foundation? Yes \_\_\_ No X Not Sure \_\_\_  
 \_\_\_ Donor Advised Fund(s) \_\_\_ Fund for Chester County \_\_\_ Don't know/Not sure

**Field/s of Interest:**

___ Arts, Culture & Humanities	___ Environment/Animal Welfare	___ Education
<u>X</u> Health	___ Human Services	___ Religion

**Organization Information:**

**Geographic Area Served** (If not all of Chester County, specify primary Chester County regions served): Our chapter serves constituents throughout Philadelphia, Eastern Pennsylvania, Southern New Jersey and Northern Delaware.

**Describe Population Served and Annual Number of People Served:** Our chapter serves more than 103,000 local constituents, including patients living with Crohn's disease and ulcerative colitis, their family, friends and caregivers, medical professionals in the IBD field (including doctors, physician's assistants, nurses, nutritionists, social workers, psychologists, and researchers). Our national resources reached 1.2 million constituents in 2018.

**Mission:** Our mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

**Proposal Summary:** Request for funding to support our ongoing essential services: research, education and support programs.

**If Capacity Building Proposal, the focus is:**

\_\_\_ Mission, Vision & Strategy \_\_\_ Governance & Leadership \_\_\_ Strategic Relationships  
 \_\_\_ Fundraising & Development \_\_\_ Technology Other: \_\_\_\_\_

<b>Annual Budget \$</b> <u>739,733</u>	<u>7</u> # of Full-Time Equivalent Paid Staff
<u>80</u> % of budget for program expenses	<u>23</u> # of Board Volunteers
<u>12.6</u> % of budget for administrative expenses	<u>189</u> # of Active Non-Board Volunteers
<u>7.4</u> % of budget for fundraising expenses	<u>1935</u> # of Volunteer Hours
<small>100 % total</small>	

**Top 3-5 funding sources:** Special Events, Take Steps Walk for Crohn's & Colitis, Individual and Foundation Donors

**Grant Amount Requested from the Community Foundation:** \$ 7,500.00

## Grant Proposal Narrative

### Executive Summary

The Philadelphia/Delaware Valley Chapter of the Crohn's & Colitis Foundation requests a \$7,500 grant from The Chester County Community Foundation to support programs impacting the lives of children and adults with inflammatory bowel diseases (IBD).

Chronic, painful, and often life-altering, IBD is estimated by the Centers for Disease Control and Prevention to affect as many as 3.1 million children and adults, or 1 in 100, in the United States. Due to the complicated factors influencing each person's IBD, the often unpredictable and debilitating course of disease, and resulting physical, emotional, psychosocial, and financial impact, IBD patients and their loved ones have unique concerns and needs. No other Philadelphia/Delaware Valley based organization serves these needs through groundbreaking programs in research, education, support, advocacy, and awareness – designed to cure IBD and improve patients' lives.

This grant will enable the Crohn's & Colitis Foundation to serve the IBD community in the Philadelphia/Delaware Valley region who look to the Foundation for the hope of a future free from Crohn's disease and ulcerative colitis.

### Crohn's Disease and Ulcerative Colitis

Crohn's disease and ulcerative colitis are major categories of IBD that result from the interaction of an individual's genes, gut microbiome, immune system, and environmental factors. Symptoms may include severe abdominal pain, persistent diarrhea, rectal bleeding, fever, malnutrition, and extraintestinal complications affecting the eyes, mouth, joints, skin, bones, kidney, and the liver. These symptoms can lead to reliance on medications not recommended for long-term use, hospitalizations, and multiple surgeries. 70% of people with Crohn's disease, and up to a third of patients who have had ulcerative colitis for 30 years or longer, will require surgery. 18% of people with IBD may develop colorectal cancer by the time they have had IBD for 30 years. Many patients suffer in silence, feeling isolated and alone in dealing with symptoms which can be embarrassing for some and are life-altering for all. IBD patients are two to three times more likely to experience psychosocial concerns, such as stress, anxiety, and depression.

Over 103,000 individuals in the Philadelphia/Delaware Valley live with IBD. IBD is most commonly diagnosed between the ages of 15 and 35 but can strike at any age. Approximately 5% to 20% of patients have a first-degree relative affected by one of the diseases, and families frequently share a similar pattern of illness. IBD can affect people of any racial or ethnic group. Research shows that people of various ethnic groups who have immigrated to the United States from countries with low incidences of disease have higher rates of developing it once living in the United States. This suggests that as yet unexplained environmental influences are at work.

### Crohn's & Colitis Foundation

**Mission and History** - The Crohn's & Colitis Foundation's mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases. When the Crohn's & Colitis Foundation was founded in 1967, very little was being done to improve treatments or to find the causes for IBD. Today, the Foundation is the largest public foundation driving research and programs designed for individuals with IBD.

**Who We Are** - The Crohn's & Colitis Foundation is the leading advocate for patients and the hub of the IBD community - which includes patients, caregivers, clinicians, researchers, volunteers, donors, commercial partners, and other non-profits. The Foundation engages the largest community of IBD patients in the country and maintains collaborations with partners that add value to IBD research or assist in improving patients' quality of life. The collaborative approach of our mission activities and world-renowned work with the best clinicians and researchers in IBD care are qualifications unique to the Foundation.

The Crohn's & Colitis Foundation is a 501(c)(3) not-for-profit organization organized under the laws of New York State. The headquarters in New York City develops and implements national programs and provides streamlined support, including in finance and operations. The Foundation currently operate 39 staffed chapters throughout the United States, and file consolidated financial and tax reports. The Foundation has earned a reputation for fiscal stability and careful stewardship of donated dollars. The Foundation proudly meets the high standards established by the Better Business Bureau Wise Giving Alliance and GuideStar, as well as other leading independent charity evaluators. More than 80 cents on every dollar raised goes towards mission, a ratio the Foundation has maintained for the past several years.

The Philadelphia/Delaware Valley Chapter has a lay volunteer Leadership Board and a Chapter Medical Advisory Committee, which advise on and guide chapter activities. Foundation staff are led by Michael Osso, president & chief executive officer, who works with the National Board of Trustees and the National Scientific Advisory Committee that provide governance to the organization.

### **Our Impact**

**Accelerating the Pace of Research** - The Foundation invests in research in order to more quickly understand what causes IBD, find a way to predict the risk of complications, find the right therapy for each patient, and discover cures. This is done through a multi-pronged approach to identify and fill gaps in IBD research, including supporting meritorious ideas proposed by researchers, driving team science, and fostering emerging research leaders. With an investment of over \$350 million to date, the Foundation has played a role in almost every major breakthrough in the treatment and understanding of IBD. Over \$12 million has been awarded to research in Pennsylvania, at institutions including Children's Hospital of Pennsylvania, University of Pennsylvania and Temple.

We accelerate research by breaking down traditional barriers to patients, data, funding, and collaborations through big data and funding streams new to the IBD field, including:

- **IBD Plexus®:** IBD Plexus is a national-scale, information exchange platform transforming how IBD research is conducted and leading to better treatments and cures faster. Gathering biosamples and/or data from 60 clinical sites, it integrates clinical, patient-reported, and molecular data from diverse initiatives; real world clinical care settings; and patients' experiences. Researchers – both in academia and at pharma companies – can dramatically accelerate their work by taking advantage of the biosamples and extensive data we have collected from thousands of patients.
- **IBD Ventures:** We invest in innovative products now in development by biotech companies and academics, to accelerate the pace of getting new treatments, devices, and diagnostic tools to clinicians and patients.

**Leveraging Years of Major, Foundation Research Investments** - The Foundation has spent the last decade making targeted, multi-million-dollar investments in areas that are important in IBD. These investments are leading to new and exciting opportunities for clinical application.

- Our \$10 million investment in the **RISK Stratification study**, the largest new-onset study completed on pediatric Crohn's disease patients, has identified biological markers that are predictive of aggressive complications that would require surgery over the next three to five years. We are translating these learnings into a diagnostic test that can be used in routine clinical care and exploring new therapeutic and diagnostic opportunities.
- Our foundational, years-long investment in **microbiome research** helped develop critical tools and techniques for understanding, measuring, and cataloging bacteria, viruses, and fungi associated with IBD. We are working with Vedanta Biosciences to build on that effort by identifying live bacterial cocktails to treat IBD – approaching the clinical realization of what could be the first FDA-approved microbiome-based treatment for IBD. There are exciting efforts happening at other biotechs and academia, built on the early microbiome work we funded.
- Years of investment in **genetic research** helped identify and refine over 240 genetic variants associated with IBD. We developed models, assessed gene levels and function, and now are funding research on one of a handful of prioritized gene targets. Working in an innovative partnership with the commercial drug discovery entity Evotec, we are investing in a project to identify drugs that will modify the gene target.

### **Catalyzing Critical Research in New Domains**

We are leading the way with millions of dollars of research investment in new, critically important areas to IBD.

- With our **Environmental Triggers Initiative**, we have put the first stake in the ground to finally understand the science behind what, why, and how diet impacts IBD, by supporting multi-million-dollar diet studies.
- We have launched initiatives to address unmet needs in IBD: to investigate biological mechanisms of **fibrosis in IBD** and to advance the development of **novel technologies** that allow continuous, non-invasive monitoring of inflammation. We are also driving new collaborations through the **Surgery Research Network**, comprising clinical sites working together to advance the surgical care of patients. The collaborative participation of sites shortens the time needed to initiate approved studies and enables clinicians to study specific patient populations and address therapeutic-related questions more efficiently.

**Inspiring and Engaging in the Journey to Create a World Free of IBD** - We bring together the largest community of IBD patients in the country and engage them in the fight against Crohn's and colitis.

- **Research input:** Patients are actively engaged in our research grant-making process, contributing clinical samples and data to accelerate research. Tens of thousands of adult and pediatric patients are currently contributing data and biosamples to cohorts on IBD Plexus, providing researchers with invaluable information and facilitating studies into new treatments and cures as never before.
- **Education:** Patient volunteers work beside our scientific advisors in the creation and review of all content produced by the Foundation. Educational information is offered to patients through our website and the IBD Help Center. The Foundation produces educational materials for patients at all ages and at all stages of their IBD journey. Materials are distributed at no cost to gastroenterologists, GI nurses, IBD patients and their caregivers, callers to the IBD Help Center, and at Camp Oasis.
- **Advocacy:** Patients work with us to advocate for public policy initiatives at state and federal levels. Foundation's activities led to the growth of the Crohn's & Colitis Caucus to 74 Members of Congress and increased federal research funding for IBD in fiscal year 2019.
- **Awareness:** Increased awareness has the potential to lead to earlier diagnosis and more effective treatments. The Foundation drives high-profile events which raise awareness and mission-critical funds. At the Philadelphia/Delaware Valley Chapter, we are hosting multiple special events and peer-to-peer fundraising campaigns, including our family-friendly Take Steps for Crohn's & Colitis Walks, the spin4 crohn's & colitis cures team relay, a Young Professionals Comedy Night and the Annual Evening of Hope Gala bringing together thousands of people from the community to have fun, spread awareness and raise funds for cures.

**Building Resiliency and Empowering Patients** - We are increasing support and education for patients and caregivers to help build resiliency and empower them to take charge of their care, essential keys to wellness. Research has demonstrated that engagement with foundations such as ours results in increased disease knowledge and resiliency, which has been consistently correlated with better health outcomes. As such, the Foundation is actively expanding its focus on patient support:

- **Support programs:** The Foundation operates a nationwide in-person support group program of over 250 groups, including in Conshohocken, Paoli, and West Chester, PA. Those who are uncomfortable discussing their condition and attending in-person groups now have the opportunity to participate in online groups.
- **Camp Oasis:** Camp Oasis is the only program of its kind for children and teens with IBD. It addresses the wide range of challenges faced by pediatric patients and offers campers the opportunity to interact in a safe and supportive environment with others in their age group. In 2019, the Philadelphia/Delaware Valley Chapter had 115 campers attend the Camp Oasis site at Camp Nock-a-Mixon in Kintnersville, PA.
- **IBD Qorus®:** Shared decision-making (between patient and provider to agree on best treatment plan) is the central element of our quality of care initiative, IBD Qorus. In 2018, we initiated a major effort amongst 30 IBD Qorus sites to identify patients at high risk of urgent care utilization, to proactively address symptoms and potentially decrease emergency room utilization and unnecessary exposure to steroids, narcotics, and radiation.

### Program Evaluation

The Crohn's & Colitis Foundation is able to fulfill its mission because of our dedicated board of trustees and National Scientific Advisory Committee (NSAC). Comprised of leading medical experts in IBD, sub-committees such as the Patient Education Committee and Pediatric Affairs Committee work closely with Foundation staff to advise, guide and evaluate various programs.

In addition, the Chapter Medical Advisory Committee (CMAC) works in conjunction with medical professionals and the non-medical communities to assist in the development and evaluation of local support and education programs for patients and professionals. CMAC provides professional insight in the formation and evaluation of a yearly calendar of chapter activities in accordance with the Crohn's & Colitis Foundation's 2017-2020 Strategic Plan.

The Crohn's & Colitis Foundation continuously collects valuable feedback from the constituents we serve, so that our programs will reach the most audience and have the most impact on the lives of IBD patients.