About the FH Foundation

The FH Foundation® is a patient-centered nonprofit organization dedicated to research, advocacy, and education of familial hypercholesterolemia (FH). Our mission is to raise awareness and save lives by increasing early diagnosis and encouraging appropriate management.

FH is a common inherited disorder that leads to aggressive and premature cardiovascular disease. For people with FH, genetic mutations make the liver incapable of metabolizing (or removing) excess LDL cholesterol, resulting in very high levels throughout life. FH is found in women, men and children of all racial and ethnic backgrounds, in an estimated one in every 250 people around the world.

FH can be diagnosed, but 85% of people born with FH are not diagnosed, leaving them at grave risk.

FH should be screened for if a person has high cholesterol and a family history of heart disease.

Up to a 20x higher risk of heart disease

FH is a life-threatening genetic condition that causes premature heart disease.

FH can be managed - there are treatments available that significantly lower the risk of early heart disease.
The FH Foundation is dedicated to improving the lives of families impacted by familial hypercholesterolemia (FH). We have a proven track record of collaborative research and impactful advocacy. Since our founding in 2011, we have focused on addressing the urgent need for diagnosis and timely care of individuals and families living with FH. We work with health system leadership, public health officials, elected representatives and insurance plans to help them understand the impact of FH on 34 million people around the world. Every program, every partnership and every day is focused on how we can improve the chances for families who have FH live a full and healthy life, while reducing the physical, emotional, and financial burdens of heart disease.

A major accomplishment in 2019 for us was successfully advocating for FH to be specifically appropriated federal funding to the United States Centers for Disease Control and Prevention to increase educational activities focused on FH.

FH affects 1 in 250 men, women and children of all races and ethnicities. Approximately 1 in 10 heart attacks at a young age are caused by FH. Today, less than half of individuals diagnosed with FH are achieving guideline-recommended treatment goals.

The cost of underdiagnosis and undertreatment of FH is early heart attacks, expensive bypass surgeries, and tragic deaths. The facts are in — a life-time burden of high cholesterol causes cardiovascular disease. Lowering LDL-C beginning in childhood can extend lives and health significantly.

The FH Foundation’s mission and commitment is to secure a healthier future for every individual born with FH. Understanding one’s genetic risk, and partnering with the right medical team, can give people up to 16 more years of disease-free life. This is why we need to educate, advocate and legislate for better care and protection of those living with FH.

Thanks to your support, the FH Foundation invests in innovative and effective solutions to address under-diagnosis and under-treatment. We continue to improve and maintain infrastructure for public health surveillance of FH in the United States through the CASCADE FH® Registry. Because of your commitment, we are making significant strides in awareness and diagnosis of FH. At the end of 2019, we saw an increase in diagnosis, with nearly 15 percent of individuals with FH in the U.S. diagnosed, up from only one percent when we first started. This is so encouraging!

Your donations and sponsorships help us actively partner with health systems, public health agencies, doctors, health care providers and individuals with FH to bring about meaningful and measurable improvements in care for families with FH. We engage every person who calls, emails, or joins our closed FH Facebook groups to provide education and support. We serve as a trusted resource for individuals seeking information on treatment options and clinical trials. We do all of this by applying 84 cents of every dollar we raise toward our mission and programs.

It is you, our dedicated friends, impacted families, and corporate and foundation sponsors, who make this important work possible.

Thank you!

Katherine Wilemon
Founder and CEO
Identify Individuals and Families with Familial Hypercholesterolemia

In October 2019, Lancet Digital Health published the results of the FH Foundation's innovative machine-learning tool called Flag Identify Network and Deliver FH (FIND FH).

In “Precision screening for familial hypercholesterolemia: a machine learning study applied to electronic health encounter data,” the authors highlight that the FIND FH model successfully scanned large, diverse, and disparate healthcare encounter databases to flag individuals with probable FH. The study shows that FIND FH can be applied to both large health claims lab databases and electronic health records — two very different types of data — and perform equally effectively in both.

The FIND FH model was run on 170 million records and identified 1.3 million individuals with possible FH.

“Precision screening for FH is now a reality in any healthcare system with electronic health records. We no longer need to screen everyone to find individuals who are at genetic risk for heart attacks and strokes.”

—Daniel R. Rader, MD
Vice Chair & Chief Scientific Advisor
The FH Foundation
Seymour Gray Professor of Molecular Medicine
Perelman School of Medicine, University of Pennsylvania
Establish FH as a Public Health Priority

The FH Foundation went to Capitol Hill with our volunteer FH Advocates for Awareness to meet with Representatives and Senators to let them know that FH, a common cause of preventable heart disease, is affecting 1 out of every 250 of their constituents. We met with 36 Congressional offices from 21 States.

Secured first-ever funding allocation to the United States Centers for Disease Control and Prevention (CDC) for FH-specific funding to increase health education and awareness of FH.

Familial hypercholesterolemia is now an eligible research topic in the Department of Defense’s Peer-Reviewed Medical Research Program, an accomplishment that would not have happened without our advocacy.

Continued our collaboration with the CDC, the Million Hearts initiative, and the National Institutes of Health in order to broaden awareness of FH as a public health priority.

“Patients with FH have the same risk as those with atherosclerotic cardiovascular disease, and when patients have both conditions, their risk increases by five times”

—Nanette K. Wenger, MD, MACC, MACP, FAHA
Emory Heart and Vascular Center

Remarks from the 2019 FH Global Summit presentation: “Science, Policy and Behavior: Necessary Ingredients for Changing Care”
Research to Improve Diagnosis and Treatment of FH

Published 4 peer-reviewed papers in scientific journals in 2019 increasing our total publications since 2014 to 25.

The FH Foundation was key partner in two NIH-funded studies:

- With Columbia University and Boston Children’s Hospital: Aims to improve FH screening in the US by identifying the health and economic value of different screening methods, as well as the optimal age for screening and use of genetic testing.

- With Geisinger Health: Leverages implementation science to determine the best methods to identify individuals with FH through machine-learning and genomic approaches, as well as develop strategies to improve family communication and cascade testing.

Enrolled 779 individuals in the CASCADE FH® Registry, bringing total enrollment to over 6,294 individuals (4,381 prospective and 1,913 retrospective) across the United States.

“Living with FH for over 30 years and seeing the impact early heart disease caused by FH has had on my family, I know the importance of finding support and information you can trust. Thanks to the FH Foundation getting the word out, my family and community are living healthy.”

—Don Davidson
FH Advocate for Awareness
Advance Scientific Insights and Knowledge

The 7th annual FH Global Summit was held in Atlanta, Georgia and focused on familial hypercholesterolemia as a prototype for precision public health. Over 280 interdisciplinary participants from 24 countries attended including experts in FH, genomics, and precision medicine, as well as healthcare practitioners, industry leaders, and individuals with FH.

Dr. Joshua Knowles, Chief Research Advisor for the FH Foundation, presented the “State of FH” in the U.S. He announced that 15% of individuals with FH have now been diagnosed with FH thanks to the work of the FH Foundation and dedicated FH experts.

Continued work to develop a Global Call to Action including reexamining the recommendations of the 1998 WHO Report on FH so that they can be implemented on a country level. Convened FH Global Summit Community from 40 countries for the 2nd annual meeting and developed consensus recommendations.

Today, 39.1 million people in the U.S. are not using statins when indicated, according to National Health and Nutrition Examination Survey data. It may be possible to prevent over 300,000 heart events per year just by increasing cholesterol management to 80% of those who are eligible for statins.

—Rear Admiral Betsy Thompson
US Centers for Disease Control and Prevention
Remarks from the 2019 FH Global Summit presentation: “Heart Disease Prevention: A Public Health Perspective”
Mobilize the FH Community

Added 32 FH Advocates for Awareness, bringing our total trained volunteers to 113 from 35 states, to share their FH story with the community, offer peer support to other individuals with FH and caregivers, deliver educational brochures and materials to local clinics and hospitals, and provide a charitable donation or arrange a local fundraiser.

With its FH advocates, the FH Foundation succeeded in getting governors in Kansas, Oregon, Colorado, New Hampshire, Louisiana, South Dakota, Florida, Indiana, Arkansas, Wisconsin, California, Michigan, Ohio, Kansas, New York and Texas to proclaim September 24 as FH Awareness Day.

Almost 600 healthcare providers in 35 countries now appear on our interactive FH Specialists Map.

Reached over 25 million people through social media via our annual FH Awareness Day campaign.

Continued a national PR and social media campaign - #FHCANTWAIT - that secured over 350 articles and reached more than 370 million people through coverage in numerous outlets including Forbes, Doctor Radio, Healio, HealthDay, Reuters and US News and World Report.

“To explain that your child has a severe cholesterol disorder does not resonate with people. However, to explain heart disease... people understand that. To say, my child has a 90% blockage in his heart is both scary to say and is real.”

—Kate Robinson
FH Advocate for Awareness
Address Barriers to Care

Worked to make sure that individuals with FH, healthcare professionals, payers and policymakers understand the urgency to optimize FH management according to the 2018 ACC/AHA Cholesterol Guideline on the Management of Blood Cholesterol.

Advocated for improved access for care. Met with the Department of Health and Human Services, Centers for Medicare and Medicaid Services (CMS), and members of Congress to ask them to support access to lower drug prices and out of pocket costs for individuals with FH and cardiovascular disease.

Published study in *Circulation: Cardiovascular Quality and Outcomes*, which found that high-risk individuals had a 16 percent increased risk of a cardiovascular event during the 11.5-month study period when prescribed PCSK9 inhibitor treatments were rejected by their insurance plan.

“High cholesterol and heart disease has impacted our family for generations. We accepted the cards dealt to us. The FH Foundation helped us realize we can stop the family cycle and beat heart disease. We have lost ENOUGH family members. People with FH can live long, healthy lives.”

—Debbie, Lana, and Vicki (sisters)
*FH Advocates for Awareness*
The FH Foundation had an impactful year in 2019 with over 84% of our revenue going toward programs or services aimed at raising awareness of familial hypercholesterolemia and saving the lives of those affected by this common genetic disorder. Your continued financial support of our mission allowed us to reach more individuals and families than ever before. In 2019, the FH Foundation invested heavily in the foundation for future programs to address the significant gaps in FH care, as well as built a community for the 34 million people worldwide with familial hypercholesterolemia.

84.4% of budget goes directly to programs!

**Revenue**
Total $3,557,190

- Unrestricted: 57%
- Restricted: 43%

**Expenses**
Total $5,012,467

- FIND FH: 22.0%
- FH Optimal Care in the U.S.: 12.6%
- Multistakeholder Initiatives: 14.8%
- Fundraising: 7.8%
- General & Administrative: 7.8%
- Community in Action: 9.5%
- CASCADE FH Registry: 25.5%
Funding Impact

47% Research
35% Advocacy
18% Education

For detailed program impact, see the following sections of the annual report:

Research
Identified individuals and families with familial hypercholesterolemia and researched to improve diagnosis and treatment of FH

Advocacy
Established FH as a public health priority and addressed barriers to care

Education
Mobilized the FH community and advanced scientific insights and knowledge

In 2019, the FH Foundation earned a Gold Seal of Transparency from GuideStar.
The FH Foundation
680 East Colorado Boulevard, Suite 180
Pasadena, CA 91101
(626) 583-4674
www.theFHfoundation.org
info@theFHfoundation.org

“I have finally found a place where I can tell my FHamily story which can save generations of FHamily members worldwide. The FH Foundation connects, supports, informs, communicates and advocates, which is exactly what people with FH need every single day. Thank you FH Foundation!”

—Eileen Kent
FH Advocate for Awareness