A Letter From Our Founder

Dear Friends,

Despite the pandemic, 2020 was a pivotal year for the FH Foundation. While we encountered challenges brought on by COVID-19, the FH Foundation adapted to the ongoing needs of our community and made significant strides to support the 1 in 250 adults and children living with FH.

Working together with our partners, supporters, advocates and the medical community, we:

• Made a renewed FH Global Call to Action by coordinating with more than 40 other organizations to impact health policy around the world. (see page 3)

• Characterized current diagnosis and treatment trends of U.S. children and teens using data from the CASCADE FH Registry. These data showed that many FH children and teens are being diagnosed too late and are often under-treated. We published these research findings to inform efforts to promote guideline-recommended pediatric screening, diagnosis, and treatment. (see page 4)

• Visited Capitol Hill with our community members to advocate for federal funding to address FH as a public health concern. (see page 7)

• Hosted our 2020 FH Global Summit virtually (due to COVID-19), in the form of live monthly webinar-formatted sessions from September 2020 to May 2021. Each session featured a renowned speaker, panel discussion and audience Q&A. (see page 9)

• Applied for two federally-funded research grants in collaboration with major research institutions. With these grants we aimed to find undiagnosed individuals and improve family screening. Both grants were fully funded and could eventually serve as model programs for other large health systems. (see page 10)

• Developed timely COVID-19 resources to assist our community in protecting themselves during these challenging times. (see page 6)

• Surpassed $30 million raised since 2012 to support the important research, advocacy, and education we carry out every day.

The pandemic raised concerns of an increase in cardiac complications for those infected with COVID-19, and of potential increased risk for people with elevated Lipoprotein(a) levels — often referred to as “Lp little a.” People with FH frequently also have an elevated Lp(a) — including myself — and thus even a higher risk for early heart disease and stroke than having FH alone. Raising awareness continues to be a key driver of our work, and the FH Foundation used this opportunity to expand our education efforts surrounding Lp(a), genetics and heart disease.

Your continued financial support of our mission allowed us to reach more individuals and families than ever before and respond quickly to the COVID-19 pandemic with information and guidance focused on individuals with FH, Lp(a), and heart disease.

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

Thank you for a remarkable year!

Katherine Wilemon
Founder and CEO
About the FH Foundation®

Overview

The FH Foundation, a patient-centered nonprofit organization, is dedicated to improving the lives of families impacted by familial hypercholesterolemia (FH). We have a proven track record of collaborative research, impactful advocacy, and educating families about FH.

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 systems 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 day is focused on creating or advancing programs and partnerships that can help improve the chances for families with FH to live a full and healthy life, while reducing the physical, emotional, and financial burdens of heart disease. We engage every person who calls, emails, or joins our online discussion groups to provide education and support. We serve as a trusted resource for individuals seeking information on treatment options and clinical trials.

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 collaborate, educate, advocate and legislate for better care and protection of those living with FH.

About FH

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 low-density lipoprotein cholesterol (LDL-C), resulting in very high levels throughout life. FH affects 1 in 250 people worldwide. It’s found in women, men, and children of all racial, ethnic, and socio-economic backgrounds. Approximately 1 in 10 heart attacks of individuals under the age of 50 are caused by FH.

Today, less than half of individuals diagnosed with FH are achieving guideline-recommended treatment goals. The cost of under-diagnosis and under-treatment of FH is early heart attacks, expensive bypass surgeries, and tragic deaths. The facts are in: a lifetime burden of high cholesterol causes cardiovascular disease. Lowering LDL-C, beginning in childhood, can improve health significantly and extend lives.
FH Global Call to Action

At our 2018 FH Global Summit, the FH Foundation brought together the original authors of the groundbreaking 1998 World Health Organization (WHO) Report on Familial Hypercholesterolemia to honor them, take stock of the progress, and reinvigorate our global efforts to address FH as a public health priority. In the two years following the 2018 FH Summit, the FH Foundation partnered with the World Heart Federation to convene more than 40 patient advocacy organizations and thought leaders from around the world. Together, we reissued an emphatic call – the FH Global Call to Action – to close the current gaps in identification and care of FH.

In 2020, “Reducing the Clinical and Public Health Burden of Familial Hypercholesterolemia: A Global Call to Action” was published in JAMA Cardiology. The Global Call to Action makes 9 public policy recommendations. As you will see in the 2020 Annual Report, the FH Foundation’s programs are addressing these priorities in the United States.
CASCADE FH Registry Research

The CASCADE FH Registry is a longitudinal observational research study conducted by the FH Foundation and our incredible clinical partners at 40 sites across the U.S. Registry research helps to quantify gaps in FH diagnosis and treatment and the consequences for cardiovascular health. The CASCADE FH Registry and our research findings inform our advocacy efforts for all 9 FH Global Call to Action public policy recommendations.

Participation in the CASCADE FH Registry has steadily increased since 2013. In 2020, we enrolled 107 new participants (the Registry was paused on April 13, 2020 due to COVID-19), bringing total enrollment to 6,401 adults and children across the United States.

Data from the Registry provide insight into current trends in FH diagnosis and treatment. The FH Foundation and our clinical partners analyzed data from the Registry among participants under 18 years of age and published our findings in the *Journal of Pediatrics* in 2020. This analysis underscored the fact that children with FH are diagnosed too late and most do not reach treatment goals. This publication serves as a tool for advocating for earlier screening, testing, diagnosis, and treatment.
The FH Foundation published five peer-reviewed papers in scientific journals in 2020 bringing our total publications since 2014 to 30. These publications contribute to the evidence base and inform better screening, testing, diagnosis, and treatment of FH. They serve as tools for awareness and advocacy to advance FH Global Call to Action recommendations.


- **Perspectives from individuals with familial hypercholesterolemia on direct contact in cascade screening,** Journal of Genetic Counseling 2020 | Schwiter, R, et al.

Because individuals with heart disease, including heart disease caused by FH, are at greater risk for worse outcomes from contracting COVID-19, the FH Foundation quickly consulted with healthcare experts and provided COVID-19 tools and resources for individuals with FH, high Lp(a), and others. We posted a letter on our website to take to the ER to explain FH and Lipoprotein(a), and held several webinars to ensure that trusted information customized to meet the needs of FH patients and their families was available.

“Without FH Foundation’s resources on the latest research with regard to COVID-19, I’d never know that should I contract it I’ll be in greater danger than the average person. The printed letter from the FH Foundation to ER doctors to guide their care for me, should I need it, is displayed for easy access on our family’s refrigerator. This information could save my life and I’m so grateful to have it.”

—Trish F.
FH Foundation Community Member
FH Advocacy

On January 28, 2020 the FH Foundation and many of our amazing community members went to Capitol Hill to ask our elected representatives to prioritize FH as a public health concern. This was the fifth year we visited Capitol Hill to raise awareness among our policy makers about the silent public health crisis posed by FH and the opportunity to prevent premature heart disease with early diagnosis and proactive treatment of this common genetic condition.

We asked Congress for funding for the CDC to address FH as a public health concern and we succeeded! As a result, the federal budget once again allocated $100,000 to the CDC to specifically address FH.

In addition, as a result of the FH Foundation’s advocacy in 2020, the House of Representatives Labor, Health, and Human Services Committee on Appropriations specifically urged the National Institutes of Health Heart, Lung, and Blood Institute to fund efforts to study FH.
FH Community in Action

In 2020, we welcomed 17 new FH Advocates for Awareness, bringing our total trained volunteers to 132 in 37 states. FH Advocates for Awareness raise awareness by sharing their FH stories with the community, advocate with policy makers, offer peer support to other individuals with FH, deliver educational resources to local clinics and hospitals, and offer insights to the FH Foundation and our partners to help us better understand the experiences and address the priorities of those living with FH.

Almost 600 healthcare providers in 35 countries can be found on our interactive FH Specialists Map. This is our #1 requested resource.

Over 7 million people have been reached through social media via our annual FH Awareness Day campaign on September 24th.

“I feel beyond fortunate to have found the Familial Hypercholesterolemia Foundation. The outreach team listened carefully to my concerns, answered all of my questions, and gave me a level of support that I have never felt in dealing with other past major medical issues. Although this journey has just begun for my family, I already feel like I have incredibly knowledgeable people on my team. How amazing to have this resource available!”

— Jennifer M.
FH Foundation Community Member
We adapted to a world with COVID-19 by hosting the 2020 FH Global Summit virtually. From September 2020 to May 2021, we hosted eight live, monthly, webinar-formatted sessions featuring a renowned speaker, panel discussion, and audience Q&A. Each session covered a current and relevant topic related to the diagnosis and care of individuals with FH and other inherited lipid disorders.

We reached more people than ever. Over 1,350 people registered for the Summit from all over the world, including almost 1,000 people from the US and more than 350 people from other countries. Fifty percent of registrants were healthcare professionals (physicians, nurses, genetic counselors, fellows, and researchers), 30% were individuals with FH or high Lp(a), and 12% were representing industry (8% were Other). Session attendance averaged over 200 attendees for the live session.

A recording of each of the sessions can be found at: summit.theFHfoundation.org. Since the broadcast, these recordings have already been viewed more than 2,500 times.

The 2020 FH Global Summit topics bridged science and clinical practice and included data and patient perspectives that informed and inspired action across a broad, passionate FH community.

The 2020 FH Global Summit sessions included:
- The Future of Genetics and Heart Disease
- Unlocking the Potential of Precision Health for Diverse Populations
- Can Behavioral Economics Drive Cardiovascular Disease Prevention?
- Lp(a) and Drivers of Inherited Risk
- New Frontiers of FH Care
- Implementing Innovations in FH Care
- FH Treatments
- Prioritizing Solutions to Prevent Inherited Cardiovascular Disease
Partnerships in Applied Research

The FH Foundation’s mission to prevent cardiovascular disease and improve the health of individuals and families with genetic risk due to FH aligns with the general mission of many research institutions. We collaborate with over 40 leading institutions in the U.S. through the CASCADE FH Registry Network and with several health systems implementing our innovative Flag/Identify/Network/Deliver FH (FIND FH®) approach using machine learning and implementation science to proactively identify individuals who could benefit from an evaluation for possible FH diagnosis.

We are proud to partner in federally funded research with several leading institutions. Our work on NIH-funded grants with Geisinger Clinic and Columbia University & Boston Children’s Hospital continued in 2020. In addition, we successfully partnered with Penn Medicine and University of Texas Southwestern (UTSW) to secure two additional federally-funded grants. Our collaboration with Penn Medicine will use the FIND FH machine learning model and behavioral economics to design and implement an effective approach to identifying, diagnosing, and treating undiagnosed FH patients. Our partnership with UTSW is focused on designing and testing a successful approach to cascade family screening in the U.S. Both grants were fully funded and could eventually serve as model programs for other large health systems.
At age 43, Scott Radabaugh underwent emergency quadruple bypass surgery that prevented a potentially fatal widow-maker heart attack. Afterwards, he learned that his arteries had clogged due to the genetic condition FH. Scott had his kids tested and discovered all three had very high cholesterol just like Scott. His daughter, Chloe, was diagnosed at age 5 with the rare and most severe form of FH – Homozygous FH.

Knowing that early diagnosis is key to treating FH and saving lives, Scott combined his love for motorcycles with his passion for raising awareness of FH, particularly among motorcycle enthusiasts. With the help of his daughter, he customized the MSL bike in FH colors with DNA strands representing the FH genes. Now, with the FH Foundation’s support, he takes the bike on the road to races and shows, raising awareness of FH and HoFH.

Learn more about the Radabaugh family and their Motorcycle Saves Lives Awareness and Fundraising effort here:

[theFHfoundation.org/motorcyclesaveslives](http://theFHfoundation.org/motorcyclesaveslives)
2020 Financial Overview

Your donations and sponsorships help us actively work with health systems, public health agencies, medical professionals, and individuals with FH to bring about meaningful and measurable improvements in care for families with FH. We do all of this while being good stewards of your financial support.

The FH Foundation had another impactful year in 2020 with more than 85.4% of our funding going toward programs or services aimed at raising awareness of FH and saving the lives of those affected by this common genetic disorder. This year, we also surpassed $30 million raised since 2012 to support our important research, advocacy, and education efforts.

85.4% of budget goes directly to programs

Revenue 2020
$3,817,745

- Unrestricted $2,099,759.75
- Restricted $1,717,985.25

Expenses 2020
$3,120,676

- Community in Action $343,274.36
- CASCADE FH Registry $468,101.40
- FIND FH $592,928.44
- FOCUS $405,687.88
- Global Network $31,206.76
- FH Global Summit $249,654.08
- Research Grants $343,274.36
- Other $218,447.32
- General and Administrative $312,067.60
- Fundraising $156,033.80

52% Research | 31% Education | 17% Advocacy

55% Revenue 2020

11% Expenses 2020
The FH Foundation’s critical work in 2020 was made possible by the contributions of individual donors and corporate sponsors who believe in our mission. Thank you!

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