Familial Hypercholesterolemia Foundation

2018 Annual Impact Report

FH FOUNDATION

Raising Awareness. Saving Lives.

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.

Up to a **20x** higher risk of heart disease

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

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

FH can be diagnosed and managed, but **90%** of people born with FH are **not diagnosed**, leaving them at grave risk.

The World Health Organization classified familial hypercholesterolemia as a public health concern in 1998. Sadly, the recommendations to prevent premature heart disease in the millions of families living with FH were never widely distributed or implemented. I often reference this report as a source of inspiration and a roadmap. In 2018, on the 20th anniversary of this initial effort to address FH, the FH Foundation brought together seven of the original authors and 35 global organizations to assess all that has been achieved and where gaps in diagnosis and care persist.

The FH Foundation's mission and commitment is to secure a healthier future for every individual born with FH. Research now shows that if a person with FH is diagnosed and begins appropriate management by the age of 18, they have on average 16 more years of life. This is why we need to continue to educate, advocate and legislate for better care and protection of those living with FH: because prevention of premature coronary heart disease, even for those at highest risk, is possible.

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 familial hypercholesterolemia. At the end of 2018, 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 and public health agencies 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 86 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!

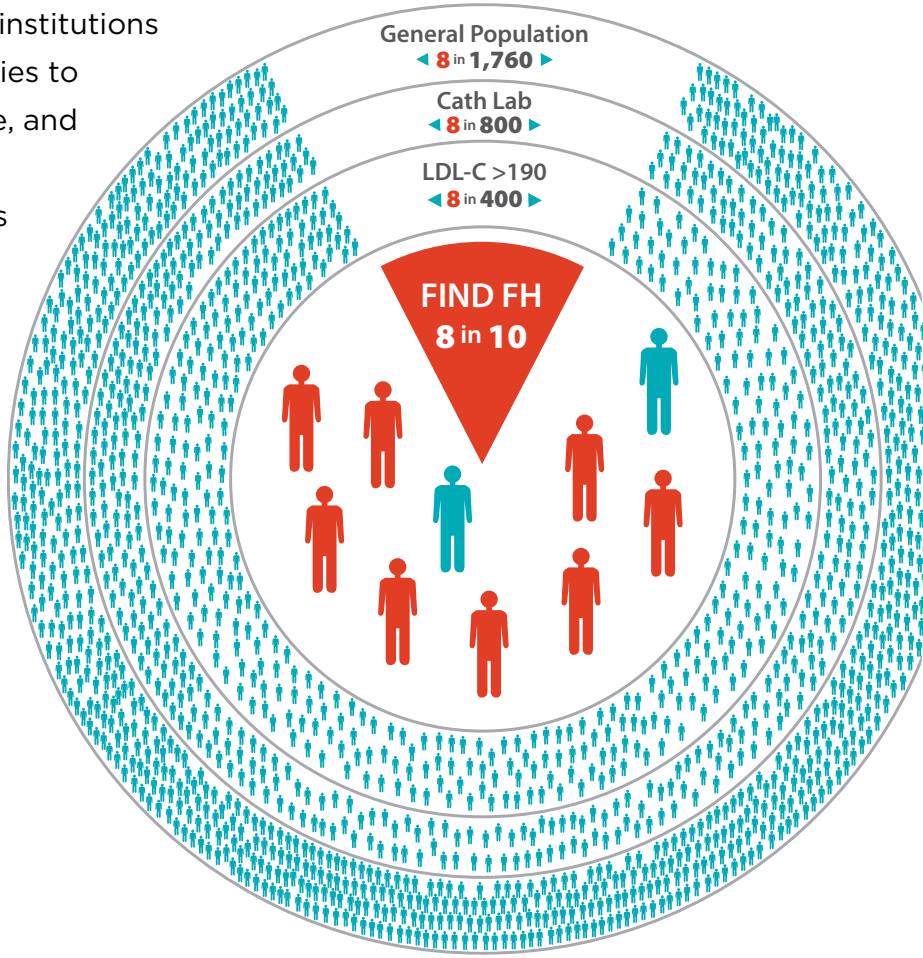
Katherine Wilemon
Founder and CEO

"I don't want to lose anyone else to heart disease, so I have made it my personal mission to bring awareness about FH to everyone I know."

—Ora W.
FH Advocate for Awareness

Identify Individuals and Families with Familial Hypercholesterolemia

- Implemented the FIND FH® machine learning algorithm, an application of artificial intelligence, to successfully identify and flag individuals with probable FH for further screening, in three major health systems in the United States (Oregon Health Sciences University, Penn Medicine, Stanford Medicine).
- Collaborated with partner institutions on implementation strategies to identify, evaluate, diagnose, and enhance the clinical management of individuals with FH.
- Screened 10 individuals to identify 8 probable FH patients, instead of screening thousands.
- Increased the number of individuals identified with the FH Diagnosis Code (E78.01) to 197,000.



Establish FH as a Priority for Public Health

Directly engaged with 15 health plans and pharmacy benefit managers to change access to care and improve understanding of FH. Developed and issued FH Foundation Guidance for Prior Authorization Criteria for PCSK9 inhibitors for FH in adults.

Met with 30 Congressional offices to ensure senators and representatives considered people with FH when voting on healthcare legislation that might compromise the privacy of genetic information or affect access to care, such as pre-existing conditions legislation.

Co-led the Cascade Screening working group of the Genomic Public Health Action Collaborative (GPHAC) at the National Academies of Sciences, Engineering and Medicine. Identified gaps in care and published recommendations for family screening for tier 1 conditions, including FH, in *Health Affairs*.

Collaborated with the Centers for Disease Control and Prevention, National Heart Lung, and Blood Institute, and Million Hearts Initiative to broaden awareness of FH as a public health priority.

> **"I have been extremely impressed by the work of the FH Foundation, educating payers by giving voice to the views of both the patients and physicians. I have been on several conference calls and, without exception at the end of each call, it was clear that the payers had a different perspective and, in most cases, this has been followed by a change in policy."**
>
> —**Christie M. Ballantyne, MD,** Baylor College of Medicine

"I wanted to participate in the PAGENT study because I could learn more about my own FH, while giving back to advance the understanding of FH."

—Dan L.
FH Advocate for Awareness

Research to Improve Diagnosis and Treatment of FH

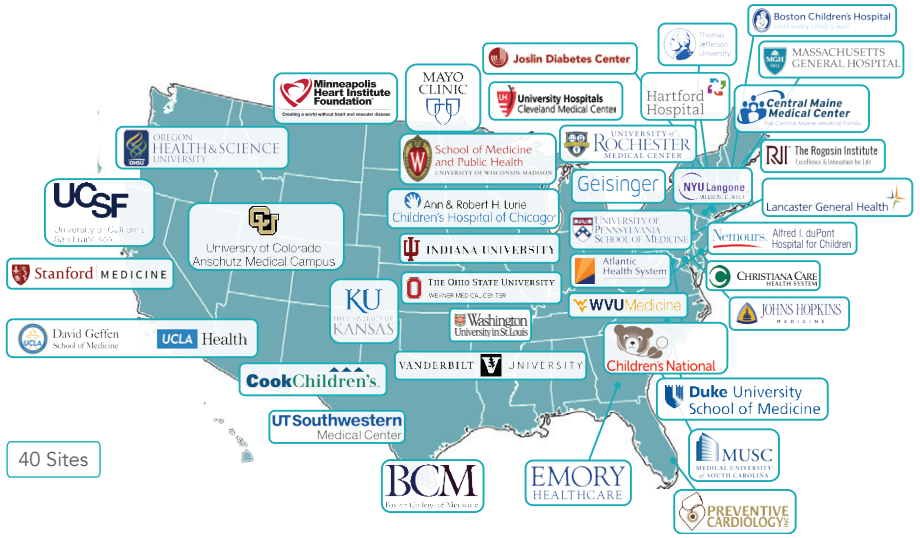
Published 6 peer-reviewed papers in scientific journals in 2018.

HEJ · Health Affairs · JACC · Human Mutation · atherosclerosis · Current Opinion in Clinical Nutrition and Metabolic Care

Increased the total to 22 publications since 2014, further establishing the FH Foundation as a leader in advancing the scientific understanding of familial hypercholesterolemia.

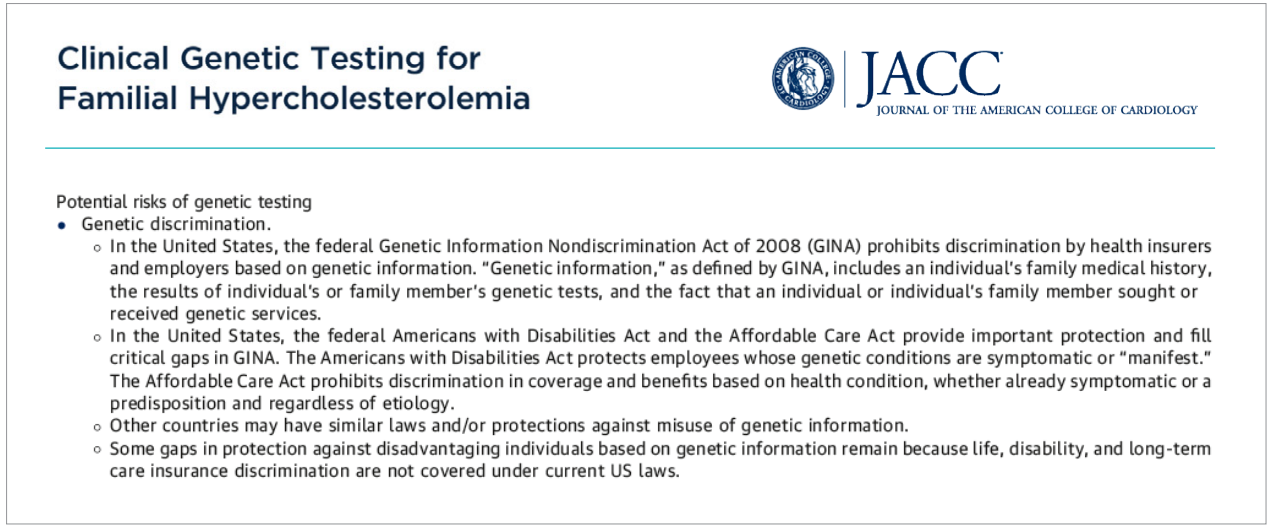
Enrolled 122 individuals in the Patient Acceptance of Genetic Testing (PAGENT) study to determine the uptake of genetic testing when barriers are removed.

Enrolled over 600 individuals in the CASCADE FH® Registry, bringing total enrollment to over 5,300 individuals across the United States.



Convene International Consensus Panel on Genetic Testing

Published a consensus statement on the application of genetic testing in FH in the *Journal of the American College of Cardiology*, the culmination of a two-year effort led by the FH Foundation and authored by an international panel of 30 cardiovascular, lipid, genetics, and advocacy experts.



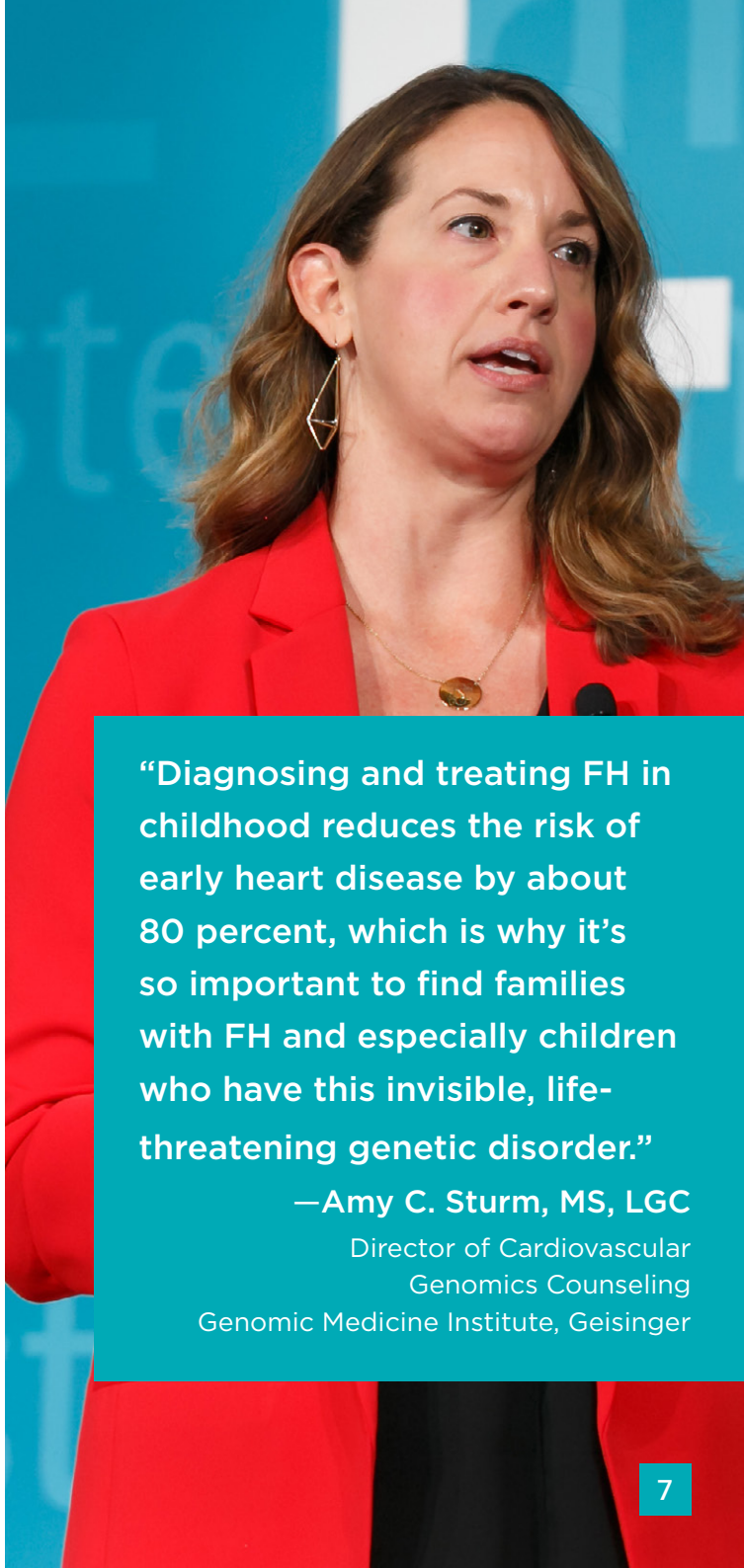
Clinical Genetic Testing for Familial Hypercholesterolemia

JACC JOURNAL OF THE AMERICAN COLLEGE OF CARDIOLOGY

Potential risks of genetic testing

- Genetic discrimination.
  - In the United States, the federal Genetic Information Nondiscrimination Act of 2008 (GINA) prohibits discrimination by health insurers and employers based on genetic information. "Genetic information," as defined by GINA, includes an individual's family medical history, the results of individual's or family member's genetic tests, and the fact that an individual or individual's family member sought or received genetic services.
  - In the United States, the federal Americans with Disabilities Act and the Affordable Care Act provide important protection and fill critical gaps in GINA. The Americans with Disabilities Act protects employees whose genetic conditions are symptomatic or "manifest." The Affordable Care Act prohibits discrimination in coverage and benefits based on health condition, whether already symptomatic or a predisposition and regardless of etiology.
  - Other countries may have similar laws and/or protections against misuse of genetic information.
  - Some gaps in protection against disadvantaging individuals based on genetic information remain because life, disability, and long-term care insurance discrimination are not covered under current US laws.

The statement recommends that genetic testing be offered to diagnose both individuals with FH and their relatives.



"Diagnosing and treating FH in childhood reduces the risk of early heart disease by about 80 percent, which is why it's so important to find families with FH and especially children who have this invisible, life-threatening genetic disorder."

—Amy C. Sturm, MS, LGC

Director of Cardiovascular Genomics Counseling
Genomic Medicine Institute, Geisinger

Advance Scientific Insights and Knowledge

Brought together over 275 world-renowned experts in FH, cardiology, lipidology, public health, and advocacy, as well as families living with FH, from 25 countries for the 6th annual FH Global Summit to accelerate best practices for FH care. Commemorated the 20th anniversary of the World Health Organization's (WHO) recognition of FH as a public health concern.

Initiated a Global Call to Action to reexamine the recommendations of the 1998 WHO Report on FH so that they can be implemented on a country level. Brought together the Global FH Community from 35 countries during the 2018 FH Global Summit and 2018 World Congress of Cardiology in partnership with the World Heart Federation.

Assessed FH knowledge among primary care physicians through 1200-person survey disseminated by the FH Foundation, the FH Ibero-American Network, and stakeholders across 11 countries.

> **"The theme for the 2018 FH Global Summit was implementation science for health impact. We know a lot about the identification and management of FH, but we haven't put all of that into practice. Too many individuals aren't diagnosed, and once diagnosed, not properly treated. We have to take what we've learned and put it into practice."**
>
> **—Daniel R. Rader, MD**
> Perelman School of Medicine, University of Pennsylvania

Mobilize the FH Community to Raise Awareness

Grew membership in our private Facebook support groups to 1,400 for HeFH and 115 for HoFH.

Trained 30 new FH Advocates for Awareness, to bring our total to 90 advocates from 35 states. Advocates educated thousands of people about FH by informing local community groups, speaking with medical students and healthcare providers, and participating in health fairs and events.

500+ 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.

Created a national PR and social media campaign – #FHCantWait – that reached 200 million people through coverage in *Forbes*, *Healio*, *Smithsonian*, *Women's Health*, and *Telemundo*.

"Thank you for the opportunity to become an FH Advocate. I learned how important early detection and appropriate treatment are for managing FH. I left with a sense of purpose and a desire to find as many people with FH as I can."

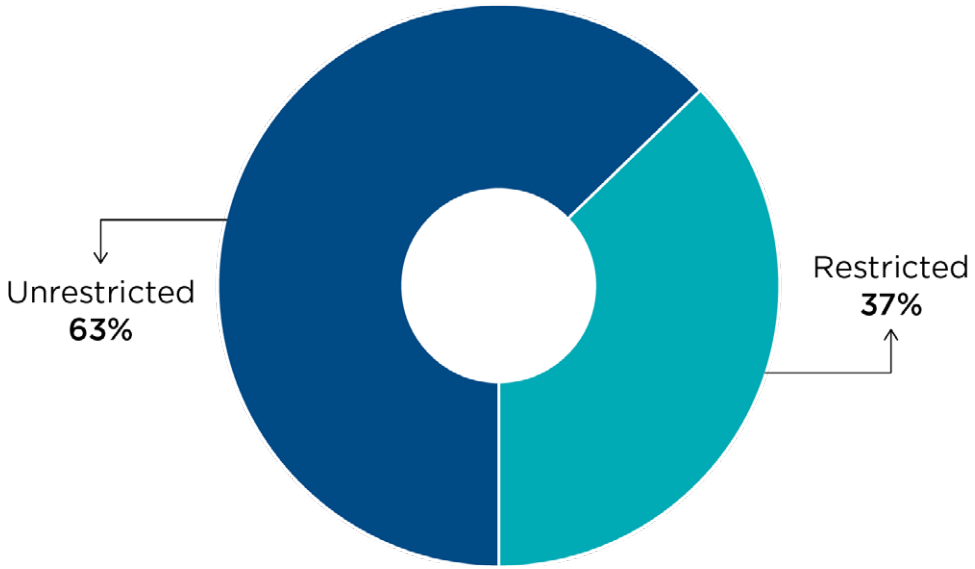
—Mike S.
FH Advocate for Awareness
Amelia's Dad

Financial Overview

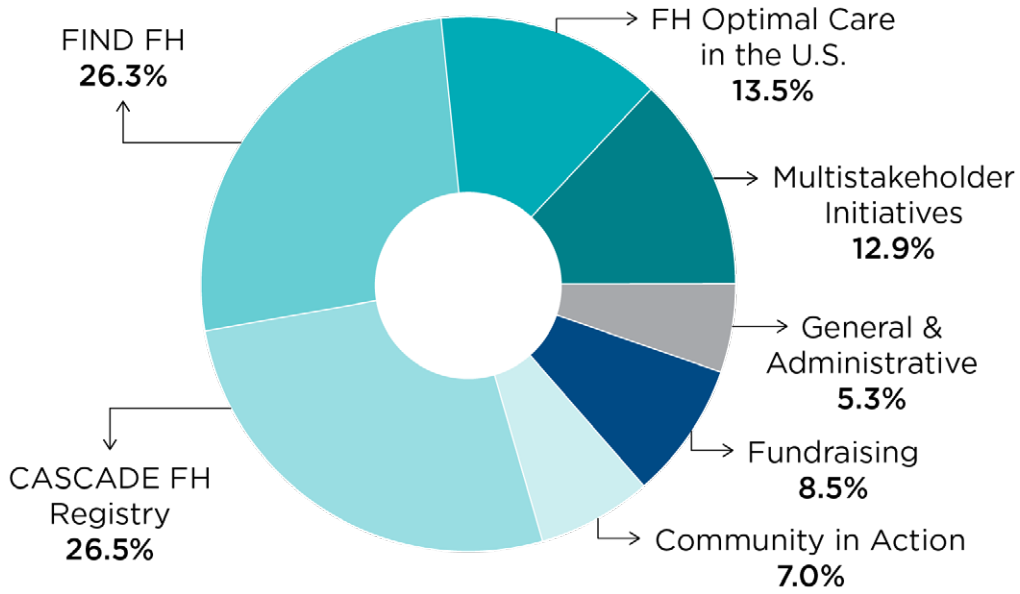
2018 was an impactful year for the FH Foundation with over 86% of our revenue going toward programs or services aimed at raising awareness of familial hypercholesterolemia (FH) and saving the lives of those affected by this common genetic disorder. Your continued financial support of our mission allowed us to reach more individuals and families than ever before.
In 2018, the FH Foundation invested heavily in the foundation for future programs to address the significant gaps in FH care, as well as build a community for the 34 million people worldwide with familial hypercholesterolemia.

86% of budget goes directly to programs!

Revenue
Total $3,045,540



Expenses
Total $5,685,786



Funding Impact

50%
Research

34%
Advocacy

16%
Education

Research

Identify individuals and families with familial hypercholesterolemia; research to improve diagnosis and treatment of FH; convene international consensus panel on genetic testing; and advance scientific insights and knowledge

Advocacy

Establish FH as a priority for public health

Education

Mobilize the FH community to raise awareness; advance scientific insights and knowledge; and identify individuals and families with familial hypercholesterolemia

In 2018, the FH Foundation earned a Silver Seal of Transparency from GuideStar.

The FH Foundation

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> **"The FH Foundation provides the bedrock that connects patients, providers and the research community. Experts become accessible to patients and families, and, as a result, the community as a whole benefits from the ability to interact and support one another. I do not think I can find the proper words to truly express my thoughts and feelings on how the Foundation has impacted and improved the lives of patients and families living with FH."**

—James A. Underberg, MD, MS

Clinical Assistant Professor, Department of Medicine, NYU Langone Health