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 the rate of early diagnosis and encouraging proactive treatment.

FH is a common, inherited disorder that can lead to aggressive and premature cardiovascular disease. For people with FH, genetic mutations make the liver incapable of metabolizing (or removing) excess LDL, 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.

Innovation. Collaboration. Vision. These are the hallmarks of the work of FH Foundation. Individuals and families with FH, clinicians, clinical experts, corporations, innovative thought leaders, researchers, and philanthropists around the world work with us to create a force far greater than the sum of its parts.

Together, we are driving the urgent changes needed to save the lives of people with FH.
“Despite an increase in overall awareness of FH, approximately 90% of individuals with FH are still undiagnosed. More than one million people with FH in the United States alone are undertreated and therefore at major risk for early cardiovascular disease, often potentially fatal. The FH Foundation is leading the way to find these individuals – and their affected family members – so that they can get the diagnosis and personalized care they need.”

~ Daniel J. Rader, MD
Seymour Gray Professor of Molecular Medicine, Perelman School of Medicine at the University of Pennsylvania; Chief Scientific Advisor, the FH Foundation.

“FH truly affects the entire family. Setting an example by being proactive and managing my own FH is the best gift I can give my own family.”

~ Anna R. Mother of Four, FH Advocate for Awareness
Dear Friends,

Every person born with familial hypercholesterolemia (FH) is on the front lines in the fight against heart disease.

FH is a common genetic condition that affects 1 in every 250 individuals and requires early identification and treatment. And yet, 90% of individuals with FH are undiagnosed. Millions of people in the U.S. and around the world are not receiving basic care for this high-risk condition. They miss out on proactive management and life-saving family screening.

Time is of the essence: untreated, FH can lead to measurable coronary artery disease even before puberty.

The vision of the FH Foundation is to assure that everyone with FH understands their condition and gets the care they need to live the fullest life possible. Thanks to your support, we are making substantial progress and the impact of our work together is tangible:

• After three years of effort, the FH Foundation’s application for specific diagnostic codes for FH and for a family history of FH was finally adopted by the Centers for Medicare and Medicaid. By the end of 2017, more than 190,000 people in the U.S. had already received the FH diagnosis code E 78.01. This delineation leads to better individual care, and is also critical at a policy level to make the FH population visible.

• In 2017, the FH Foundation’s CASCADE FH National Registry became one of the largest adult and pediatric FH longitudinal registries. We are increasing the scientific understanding of the immense cardiovascular disease burden on the FH population in the United States. Although individuals enrolled in the CASCADE FH Registry are receiving attention at top specialty clinics, diagnosis for this group often occurs after they have had a clinical heart-disease event. In addition, there are significant disparities in care for women, African Americans, Asians, and Hispanics. The FH Foundation is now using this information and working with health system partners to improve care.

When I started the FH Foundation, there was no FH community. Seven years later, we have built a strong community of engaged FH individuals, dedicated physicians, nurses, genetic counselors, sponsors and public health champions, not only in the U.S., but throughout the world. Thanks to you, our accomplishments in 2017 were significant. The pages of this annual report are filled with achievements and successes that you helped to make possible.

As a public charity, the FH Foundation relies upon generosity and commitment like yours to support our efforts to save lives today and for generations to come. We are honored to be called to this noble cause and to work with a dedicated scientific and philanthropic community.

With warmest regards,

Katherine Wilemon
Founder/CEO
2017 Key Achievements

IDENTIFY
INDIVIDUALS AND FAMILIES WITH FH

Until October 2016, familial hypercholesterolemia was an invisible disorder. The FH Foundation advocated for the adoption of a specific International Classification of Disease code for FH. As a direct result of these efforts, the Centers for Medicare & Medicaid Services approved ICD-10 E78.01. Now, more than 190,000 with FH have received the new ICD-10 code.

Nevertheless, 90% of individuals with FH still have not received an accurate diagnosis. Central to our mission, the FH Foundation developed FIND FH (Flag. Identify. Network. Deliver.) This cutting-edge initiative employs machine-learning technology to a HIPPA-compliant database to identify individuals with medical profiles consistent with FH. Now we are implementing these findings in partnership with healthcare providers and lab companies to reach out to more than one million people in the United States who have this life-threatening disorder.

“I finally found help after 50 years - an organization that talks to me about me and my FH. I have soldiers in my corner now.”

- Patricia Y.
US Army, Retired
FH Advocate for Awareness
ADVANCE
SCIENTIFIC INSIGHTS AND KNOWLEDGE
TO INFLUENCE CARE AROUND THE GLOBE

- 26 world-renowned experts in FH, cardiology, lipidology and related fields presented the latest research to nearly 250 physicians, researchers, people with FH and other key stakeholders at the invitation-only 2017 FH Global Summit in Miami, Florida in September.

- The Meeting of the Americas held in conjunction with the FH Global Summit convened 38 stakeholders from 11 countries to begin assessing FH knowledge among physicians throughout North, Central and Latin America.

- FH educational resources and materials are now available in 11 languages.

- The FH Foundation convened clinicians, geneticists, genetic counselors and other experts from 11 countries for the second international meeting to develop a consensus statement with recommendations and considerations for genetic testing for familial hypercholesterolemia.

“The Summit was fantastic, the most exciting meeting that I have participated in regarding familial hypercholesterolemia. From the scientific content to the networking activity, all the details were perfect.”

- Pablo Corral, MD
  Instituto Clínica Médica, Argentina
The FH Foundation published 4 peer-reviewed papers in scientific journals in 2017. This brings the total publications to 15 since 2014, further establishing the FH Foundation as a leader in advancing scientific understanding of FH.

The FH Foundation is a member of the Genomics and Public Health Action Collaborative (GPHAC) at the National Academies of Sciences, Engineering, and Medicine, co-leading the Cascade Screening Working Group to identify gaps in research and barriers to implementation, and enable opportunities to accelerate cascade family screening in the U.S. for all Tier 1 conditions, including FH.

More than 4,700 people are now entered into the CASCADE FH Registry, established by the FH Foundation in 2013. It is the only FH registry in the U.S. that collects longitudinal data. The Registry provides researchers with data that lead to insights into gaps in care and effective treatment for individuals with FH.

37 leading heart centers and lipid clinics around the country are currently enrolling individuals with FH.

"The CASCADE FH Registry is the foundation of the FH Foundation’s work. You can’t know what to do until you have examined where you are. We are learning about critical gaps in care and then driving policy changes to address those needs."

- Joshua W. Knowles, MD, PhD
  Assistant Professor of Medicine, Stanford University; Chief Medical Advisor, The FH Foundation
We conducted and published research in *Circulation* that showed that 63% of individuals with FH who were prescribed a PCSK9 inhibitor – a potentially life-saving therapy – had been denied coverage by their insurance plan.

Our analysis of data in the CASCADE FH Registry revealed that Blacks, Asians, and women receive the poorest care. Blacks were diagnosed with FH at older ages than any other race/ethnicity. Asians and Blacks were 30-50% less likely than Whites to achieve adequate LDL-C reduction. When compared to men, women were 34% less likely to receive any statin therapy, 40% less likely to be on a high-intensity statin, and 20-30% less likely to achieve adequate LDL-C reduction.

"We have to do everything possible to close the gaps. Gaps between what we don’t know and what we do; gaps between what is prescribed and what is actually dispensed; gaps between what we tell our patients to do and what they are able to afford and accept."

~ George Mensah, MD, FACC
Director, Center for Translational Research and Implementation Science; Immediate Office of the Director, National Heart, Lung, and Blood Institute

These findings help focus our work on the areas of critical need – now and in the future.
MOBILIZE
THE FH COMMUNITY

18 new FH Advocates for Awareness attended our two-day training workshop. These individuals who are affected by FH volunteer to help raise awareness of FH, inform our work and offer peer support. 60 Advocates made appearances at health fairs, service clubs, hospital Grand Rounds, local television and medical conferences.

Private FH Facebook Group membership reached 900 and the private HoFH group membership reached 100. The FH Foundation public Facebook page has 12,000 followers.

70 people raced and raised nearly $90,000 for our first virtual Race for FH fundraiser.

100 people affected by FH came together for learning and community at our Family Forums in Philadelphia, Dallas and Miami.

EDUCATE
INDIVIDUALS WITH FH, FAMILIES AND PHYSICIANS

4 new educational webinars were made available to people with FH: Heart Disease in the Family, Living with Homozygous Familial Hypercholesterolemia, Insurance 101 and FH and Pregnancy.

Individuals with FH, caregivers, and clinicians have access to our FOCUS (FH Optimal Care in the U.S.) Multimedia Tool Kit (including our Navigating Insurance Guide) to support them in their healthcare decision making.

460+ healthcare providers now appear on our interactive FH Specialist Map around the world.

3,000 healthcare providers employed the newly launched FH Diagnosis App.

“We found out that our son Max had HoFH when he was one. It was pretty scary to be out there on our own. The FH Foundation gave us information that was accurate and up to date. They are so important to everyone in the FH Community.”

~ Jonathan K.
Software Product Developer
FH Advocate for Awareness
Max’s Dad
ADVOCATE FOR POLICY CHANGES TO ENSURE ACCESS TO THERAPY

In 2017, FH Advocates for Awareness, along with FH Foundation staff, visited more than 20 Congressional offices on Capitol Hill to raise awareness about FH as a public health concern.

We worked with federal agencies such as the Centers for Disease Control and Prevention, Federal Food and Drug Administration and more to advocate for FH-related policy changes. Our team engaged with healthcare providers, healthcare systems, payers and pharmacy benefit managers – to help ensure that people with FH receive optimal care, and that they have access to recommended therapies.

Thanks to the FH Foundation’s efforts, a major pharmacy benefits manager changed their Prior Authorization criteria, making it dramatically easier for people with FH to access recommended therapies.

RAISE AWARENESS

The month-long campaign leading up to FH Awareness Day on September 24 reached an audience of 32 million.

More than 200 articles about FH appeared in the media, including Wall Street Journal, US News and World Report, Medscape, Women’s Health, and more, reaching a potential audience of more than 200 million people.
FINANCIAL OVERVIEW

With the help of supporters who have invested in our mission, the FH Foundation is financially stable and positioned for future success. This makes it possible for us to sustain and expand the impact of our programs to address the significant gaps in understanding and care for the 30 million people worldwide with familial hypercholesterolemia.

“The work of the FH Foundation is possible only because of our thoughtful, generous supporters. We can’t possibly express the depth of our gratitude nor overstate the impact you have on the lives of people with FH.”

- Katherine Wilemon, Founder/CEO

Revenue and Expenses – 2013 through 2017

<table>
<thead>
<tr>
<th>Year</th>
<th>Revenue (Dollars in thousands)</th>
<th>Expenses (Dollars in thousands)</th>
<th>Total (Dollars in thousands)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>$765</td>
<td>$1,050</td>
<td>$3,122</td>
</tr>
<tr>
<td>2014</td>
<td>$3,202</td>
<td>$1,457</td>
<td>$4,659</td>
</tr>
<tr>
<td>2015</td>
<td>$4,348</td>
<td>$3,182</td>
<td>$7,530</td>
</tr>
<tr>
<td>2016</td>
<td>$6,132</td>
<td>$4,090</td>
<td>$10,222</td>
</tr>
<tr>
<td>2017</td>
<td>$4,069</td>
<td>$4,069</td>
<td>$8,138</td>
</tr>
<tr>
<td>Total</td>
<td>$18,516</td>
<td>$14,817</td>
<td>$33,333</td>
</tr>
</tbody>
</table>

*Audit Pending

Board of Directors

William A. Neal, MD
Chairman
Robert C. Byrd Health Sciences Center West Virginia University
Stacey R. Lane, JD, MBE
Vice Chair
Seth J. Baum, MD
Secretary and Treasurer
Preventive Cardiology Inc.
Joshua W. Knowles, MD, PhD
Chief Medical Advisor
Stanford University
Katherine A. Wilemon
Founder/CEO

Daniel J. Rader, MD
Chief Scientific Advisor
Perelman School of Medicine
University of Pennsylvania
Barry A. Brooks, JD
Board Member
Paul Hastings, LLP
Allison Jamison
Board Member
Duke University
Michael D. Shapiro, DO
Board Member
Oregon Health & Science University
Maria E. Sophocles, MD
Board Member
Women’s Healthcare of Princeton

Scientific Advisory Board

Christie M. Ballantyne, MD
Baylor College of Medicine
Samuel S. Gidding, MD
Nemours/DuPont Hospital for Children
John R. Guyton, MD
Duke University School of Medicine
Linda C. Hemphill, MD
Massachusetts General Hospital Heart Center
Paul N. Hopkins, MD, MSPH
University of Utah Health Care
Lisa C. Hudgins, MD
The Rogosin Institute

Joshua W. Knowles, MD, PhD
Stanford University
Patrick M. Moriarty, MD
University of Kansas Medical Center
Daniel J. Rader, MD
Perelman School of Medicine
University of Pennsylvania
Michael D. Shapiro, DO
Oregon Health & Science University
Knight Cardiovascular Institute
James A. Underberg, MD
New York University Langone Medical Center
Karol E. Watson, MD
Geffen School of Medicine, University of California of Los Angeles

In 2017, the FH Foundation earned a Silver Seal of Transparency from Guidestar.
“The FH Foundation is a driving force that has worked strategically and effectively to engage stakeholders to initiate significant and lasting change in how FH is understood and treated. It is inspiring to think of how many lives have been saved – and will be saved in the future - because of their efforts.”

- Laurence S. Sperling, MD, FACC, FAHA, FACP, FASPC
  Professor of Medicine, Division of Cardiology,
  Emory University School of Medicine