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TITLE: Familial Hypercholesterolemia in the United States: Evaluating a Centralized Cascade Screening Model to Improve Early Diagnosis

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14. ABSTRACT

Cascade (family) screening remains the best method to identify individuals with Familial Hypercholesterolemia. The purpose of this project is to use implementation science methods to test a centralized approach to cascade screening, similar to the most successful program in the world (Netherlands), and assess its cost-effectiveness. Our scope includes two centers in the Dallas, TX, area from which FH patients will be recruited to participate. Thus far, we are nearly complete with Aim 1 which involves assessing barriers and facilitators of cascade screening via semi-structured interviews of patients and providers. We have developed an implementation blueprint, and once these interviews are analyzed, we will then use intervention mapping to adapt the centralized cascade screening model for the US. We anticipate starting Aim 2 in the next few months. We have already begun Aim 3, which will demonstrate the cost effectiveness on cascade screening in the US.

15. SUBJECT TERMS

Familial Hypercholesterolemia; Cascade screening; family screening; hypercholesterolemia; cholesterol; lipids; LDLR; LDL-C; LDL-receptor; cost-effectiveness; cardiovascular disease

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TABLE OF CONTENTS

Page 3

1. **INTRODUCTION:** Familial hypercholesterolemia (FH) is an autosomal dominant condition affecting ~1:250 individuals, characterized by markedly elevated low-density lipoprotein-cholesterol (LDL-C) and an increased risk of premature atherosclerotic cardiovascular disease (ASCVD). Less than 15% of FH cases in the US are identified despite a Tier 1 indication from the Centers for Disease Control and Prevention for early detection, cascade screening (i.e., screening blood relatives), and early intervention. In contrast, the Netherland's national FH screening program detected > 70% of FH cases – many as children - thanks to a systematic approach to cascade screening (i.e. the Dutch model). The key components to their approach were centralized coordination of family interactions and patient engagement outside of usual healthcare settings by their "Foundation for Tracing FH." These efforts were cost-effective and led to early interventions (i.e. lipid lowering therapies) for individuals with FH, reducing their ASCVD risk to levels similar to the general population. An ***urgent need*** exists to establish a feasible and cost-effective cascade screening model in the US, without which upwards of 1 million FH individuals will remain undiagnosed and undertreated, leaving them at high risk for ASCVD events (and their high costs to the healthcare system), early death, and lost productivity as young and middle-aged adults. Currently, only 4-25% of families participate in cascade screening as evidenced by data we aggregated from existing US research efforts to do cascade screening (at UT Southwestern Medical Center, University of Pennsylvania, Geisinger, West Virginia University, and Mayo Clinic). To improve this low uptake, the centralized Dutch model is promising but has not been tested in the US. Before broader implementation the centralized cascade screening model requires further adaptation to account for differences between the Dutch and US context, especially as it relates to barriers and facilitators experienced by US FH patients – including underrepresented populations (i.e., rural and racial/ethnic minority populations) and the diverse healthcare system of the US (i.e. multiple payers, varying public health policies). Our ***overall objective*** is to further develop our centralized cascade screening model for implementation in the US and demonstrate its feasibility and cost effectiveness. **Our central *hypothesis* is that an adapted, centralized approach will show efficacy and value as a cascade screening model for the US FH population.** To test this hypothesis, we propose following ***specific aims***: **Aim 1. Utilize intervention mapping techniques to adapt the centralized cascade screening model for FH populations in urban and VA settings. Aim 2. Implement centralized cascade screening at two sites (UT Southwestern and North Dallas VA). Aim 3. Evaluate the value of centralized cascade screening in the US.**

2. **KEYWORDS:** Familial Hypercholesterolemia; Cascade screening; family screening; hypercholesterolemia; cholesterol; lipids; LDLR; LDL-C; LDL-receptor; cost-effectiveness; cardiovascular disease

3. **ACCOMPLISHMENTS:**

- **What were the major goals of the project?**

		Study site.				
Specific Aim 1: Utilize intervention mapping techniques to adapt the centralized cascade screening model for FH populations in urban and VA settings.	Timeline	1	2	3	4	5
Major Task 1 Perform qualitative interviews of human patients and providers to assess barriers and facilitators of cascade screening the US	Months					
Subtask 1: Obtain (centralized) IRB/ HRPO approval for entire study (all Aims)	1	X				
Subtask 2: Develop interview guides	1-3			X		
Subtask 3: Recruit patients (n = 20) and providers (n = 10) to participate in telephone interviews	3-9	X	X		X	
Subtask 4: Perform Telephone Interviews (n = 30)	3-9			X		
Subtask 5: Key summary report of interviews	9-12			X		
Major Task 2: Apply intervention mapping to develop implementation strategies overcoming the barriers and facilitators						
Subtask 1: Adapt centralized model with panel of advisors	9-15	X	X	X	X	X
Milestone(s) Achieved:	• ***Major task 1, Subtask 1 100% complete*** • ***Major Task 1 Subtask 2 100% complete*** • ***Major Task 1 Subtask 3 99% complete*** • ***Major Task 1, Subtask 4 99% complete*** • ***Major Task 1, Subtask 5 25% complete*** • ***Major Task 2, Subtask 1 50% complete***					

Specific Aim 2: Implement centralized cascade screening at two sites (UT Southwestern and North Dallas VA)populations in urban and VA settings.	Timeline	1	2	3	4	5
Major Task 1 Perform centralized cascade screening.	Months					
Subtask 1: Recruit FH Probands (n = 100)	12-42	X			X	
Subtask 2: Recruit relatives of FH Probands for FH screening	12-42		X			
Subtask 3: Screen relatives with lipid measurements and genetic testing	12-42	X			X	
Major Task 2: Evaluate processes and outcomes of centralized cascade screening utilizing the RE-AIM framework.						
Subtask 1: Evaluate "Reach": number of family members screened (statistical analyses)	42-48	X				
Subtask 2: Develop interview guides for study participants (n = 20) and study staff (n = 2)	36			X		
Subtask 3: Recruit study participants (n = 20) for telephone interviews	36-42	X			X	
Subtask 4: Conduct telephone interviews (n = 22)	36-42			X		
Subtask 5: Key summary report of telephone interviews	42			X		

Specific Aim 3: Evaluate the value of centralized cascade screening in the US.	Timeline	1	2	3	4	5
Major Task 1 Perform cost-effectiveness analyses	Months					
Subtask 1: Model cost-effectiveness of FH cascade screening in the US.	42-48					X
Milestone(s) Achieved:	• ***Major Task 1, Subtask 1: 60% complete***					

- **What was accomplished under these goals?**
  - Aim 1, Major task 1:
    - Since the prior annual report, semi-structured interviews were conducted with patients and providers (Table 1). The interviews are nearly complete with only one patient remaining to be interviewed. We have started analyzing the interviews: each interview has been transcribed and codebook has been developed.

Table 1. Characteristics of individuals recruited for Aim 1, Major Task 1, Subtasks 3 and 4

Characteristic	Patients (n = 19)	Providers (n= 10)
Women	12	6
Ethnicity/Race	14 Non-Hispanic White 3 African American 1 Japanese 1 Hispanic White	7 Non-Hispanic White 1 South Asian 1 African American
Hospital affiliation	8 Veterans Affairs 8 UT Southwestern Medical Center 3 Parkland Health Hospital System	4 UT Southwestern 3 Veterans Affairs 3 Other
Additional details		1 Primary Care Provider 1 Pediatric Endocrinologist 2 Preventive Cardiologist 1 Adult Endocrinologists 2 Genetic Counselors 3 Midlevel providers

  - Aim 1, Major task 2:
    - Over multiple meetings in April and May 2023, we completed a major component of this aim: developing an implementation blueprint (Figures 1 and 2). This blueprint will be adapted further once results of the interviews have been analyzed.
    - We have begun adapting the existing Familial Hypercholesterolemia (FH) registry managed by the Family Heart Foundation (Figure 3). This registry did not previously contain the

necessary methods to track related individuals, a needed method for the cascade screening we will be conducting in Aim 2.

- The Family Heart Foundation has developed communication materials that can be utilized via postal mail or email (see Appendix). These materials are key for returning results to patients as well as their providers.

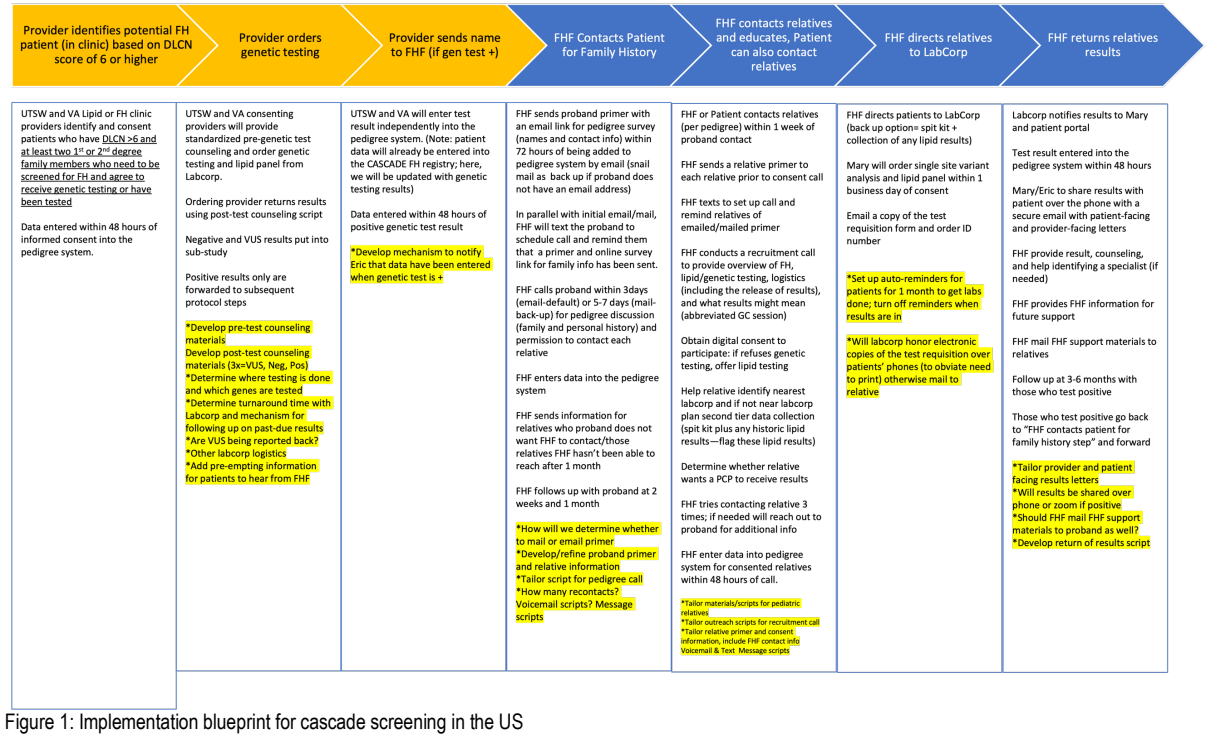

Figure 1: Implementation blueprint for cascade screening in the US

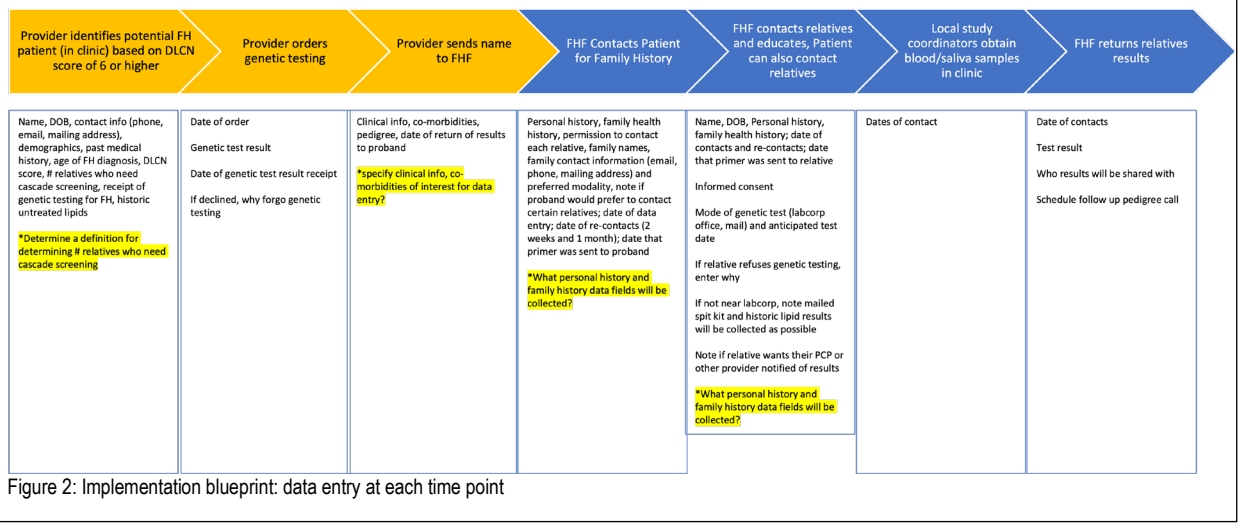

Figure 2: Implementation blueprint: data entry at each time point

- Aim 3, Major Task 1

  - Although not scheduled until the final year of the proposal, we began Aim 3 in 2022. In this quarter, we made significant progress and have developed the necessary model.

  - The first step was to establish a working group for the economic studies. This group includes researchers who are specifically knowledgeable about FH and cascade

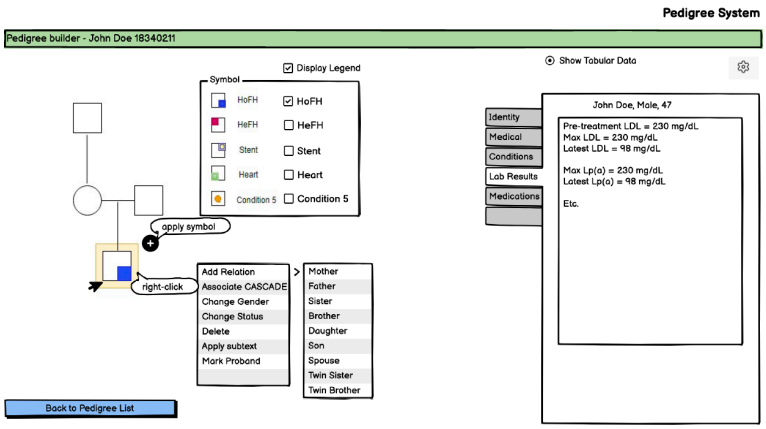

Figure 3: Pedigree System being developed to add on the existing FH registry managed by the Family Heart Foundation

screening for FH as well as researchers with specific knowledge and experience in cost effectiveness analysis. This group meets biweekly.

- The key manuscripts include:
  - Chen and Hays, Cost-effectiveness analysis of alternative screening and treatment strategies for heterozygous familial hypercholesteremia in the United States. International Journal of Cardiology 2015;181:417-424.
    - There are deficiencies with this paper both in the modeling and cost inputs which limit its applicability.
  - Jackson et al, Cost-effectiveness of cascade genetic testing for familial hypercholesterolemia in the United States: a simulation analysis. American Journal of Preventive Cardiology 2021: doi.org/10.1016/j.ajpc.2021.
    - This study improved on the paper by Chen et al, but the costing in the study was limited as were estimation of event rates.
  - Ademi et al. Cost-effectiveness and return on investment of a nationwide cost-finding program for familial hypercholesterolemia in children in the Netherlands. JAMA Pediatrics: doi:10.1001/jamapediatrics.2023.0763.
    - This recent paper is perhaps the most important one to date considering cost-effectiveness of cascade screening, but it is only applicable to the Netherlands.
  - Spencer et al. Cost-effectiveness of population-wide genomic screening for familial hypercholesterolemia in the United States. Journal of Clinical Lipidology: doi.org/10.1016/j.jaci.2022.07.014.
    - This is a critical paper of cost-effectiveness of screening for FH, but it is population-wide rather than based on cascade screening.
  - Luirink et al. 20-year follow-up of statins in children with familial hypercholesterolemia. N Engl J Med 2019;381:1547-1556.
    - This is a critical paper on 20 year event rates in patients with FH identified by cascade screening who were treated and their parents who were not.
- This next step was to create a model which can be incorporated into software (TreeAge) to perform the Markov modeling. Once informed by the literature, the basic model was defined and agreed to by the working group.
- This next step was to decide on input values for the model. The paper by Luirink will inform the event rates. The costs of cascade screening management will be provided by the Family Heart Foundation. Outpatient costs and hospitalization costs and drug will be informed by existing databases such as the National Inpatient Sample and Redbook wholesale acquisition costs. Disutilities of events will be informed by the medical literature.
- Programming in TreeAge will began in the third quarter of 2023. The outcome will be the incremental cost effectiveness ratio, which is the cost per quality adjusted life year gained. The distribution will be assessed the Markov model and displayed in the cost-effectiveness plane and in cost-effectiveness acceptability curves. There will be sensitivity analysis of around key input variables, which will be displayed as tornado

diagrams. The distribution of the ICER for the distribution of all variables will be assessed by probabilistic sensitivity analysis.

- **What opportunities for training and professional development has the project provided?**
    - Nothing to report
- **How were the results disseminated to communities of interest?**
    - Nothing to Report
- **What do you plan to do during the next reporting period to accomplish the goals?**
    - Complete 100% of Aim 1
        1. Conduct the final telephone interview for Aim 1 and analyze the data.
        2. With help from the Panel of Advisors, apply intervention mapping to develop implementation strategies overcoming the barriers and facilitators – from the data accumulated in telephone interviews - for FH cascade screening in the US.
        3. Finalize the implementation blueprint
        4. Finalize the FH registry managed by the Family Heart Foundation
        5. Adapt – based on results from the telephone interviews – communication materials developed by the FH Foundation
        6. Publish the results of telephone interviews and adaptation of the FH cascade screening model.
    - Complete 25-50% of Aim 2
        1. Adapt our protocol based on the results of Aim 1
        2. Amend IRB/HRPO documents to reflect any changes.
        3. Begin enrolling FH probands into the study
        4. Begin recruiting family members of enrolled FH probands
    - Complete 100% of the cost-effectiveness analysis for Aim 3

4. IMPACT:

   - What was the impact on the development of the principal discipline(s) of the project?
     - Nothing to Report
   - What was the impact on other disciplines?
     - Nothing to Report
   - What was the impact on technology transfer?
     - Nothing to Report
   - What was the impact on society beyond science and technology?
     - Nothing to Report

5. CHANGES/PROBLEMS:

   - Changes in approach and reasons for change
     - No major changes were made in the approach.
   - Actual or anticipated **problems or delays and actions or plans to resolve them**
     - The project was delayed by roughly 1 year due to IRB/HRPO approval process, which was a lengthy since the study includes 5 sites. We will focus on conducting Aim 2 faster and we have begun Aim 3 (originally planned for year 4) now so that the project may still finish on time.
     - We have experienced a delay in Aim 1 due to the need to file Data Use/Sharing Agreements between the North Texas VA and UNC. This slowed down enrollment for the telephone interviews in Aim 1 but once resolved, enrollment has caught up.
   - Changes that had a significant impact on expenditures
     - None
   - Significant changes in use or care of human subjects, vertebrate animals, biohazards, and/or select agents
     - None
   - Significant changes in use or care of human subjects
     - None
   - Significant changes in use or care of vertebrate animals.
     - None
   - Significant changes in use of biohazards and/or select agents

- None

6. PRODUCTS:

- **Publications, conference papers, and presentations**
  - Nothing to report
- **Website(s) or other Internet site(s)**
  - Nothing to report
- **Technologies or techniques**
  - Nothing to report
- **Inventions, patent applications, and/or licenses**
  - Nothing to report
- **Other Products**
  - Nothing to report

7. PARTICIPANTS & OTHER COLLABORATING ORGANIZATIONS

1. **What individuals have worked on the project?**

Key Study Personnel (Include Degrees and Credentials)	Study Roles and Responsibilities
Name: Zahid Ahmad, MD (30% effort) Affiliated Institution: UT Southwestern Medical Center	Study Role(s): Principal Investigator Responsibilities: Provide leadership in all aspects of the study
Name: Chul Ahn, PhD (1% effort) Affiliated Institution: UT Southwestern Medical Center	Study Role(s): Co-Investigator Responsibilities: Provide statistical support
Name: Marina Cuchel, MD, PhD (1% effort) Affiliated Institution: University of Pennsylvania	Study Role(s): Consultant Responsibilities: Serve as advisor and provide guidance for methodology
Name: Laney Jones, PharmD, MPH (1% effort) Affiliated Institution: Geisinger Clinic	Study Role(s): Consultant Responsibilities: Development and analyses of qualitative interviews
Name: Paul Kolm, PhD (5% effort) Affiliated Institution: Medstar Health Research Institute	Study Role(s): Co-Investigator Responsibilities: Define outcomes and interpret results
Name: Mary McGowan, MD (10% effort) Affiliated Institution: FH Foundation	Study Role(s): Co-Investigator Responsibilities: Overall coordination and supervision of all aspects of the study for the FH Foundation
Name: Megan Roberts, PharmD (20% effort) Affiliated Institution: University of North Carolina	Study Role(s): Co-Investigator Responsibilities: Overall coordination and supervision of implementation science activities

- **Has there been a change in the active other support of the PD/PI(s) or senior/key personnel since the last reporting period?**
  1. Nothing to Report.

2. **What other organizations were involved as partners?**

Family Heart Foundation
959 E. Walnut Street, Suite 220. Pasadena, CA 91106
Site PI/POC: Mary McGowan
Contribution: Collaboration

University of North Carolina at Chapel Hill
104 Airport Drive, Suite 2200, Chapel Hill, NC 27599
Site PI/POC: Megan Roberts
Contribution: Collaboration

Medstar Health Research Institute, Inc.
6525 Belcrest Road, Suite 700, Hyattsville, MD 20782
Site PI/POC: William Weintraub
Contribution: Collaboration

FH Foundation
959 E. Walnut Street, Suite 220, Pasadena, CA 91106
Site PI/POC: Mary McGowan
Contribution: Collaboration

Dallas VA Research Corporation
4500 S. Lancaster Road, 151C, Dallas, TX 75216
Site PI/POC: Kyaw Soe
Contribution: Collaboration

Appendix

September 20, 2023

Dear Healthcare Professional,

Your patient's relative has been diagnosed with Familial Hypercholesterolemia (FH).

FH is a genetic condition that causes very high lifelong LDL-cholesterol levels and is associated with increased risk for heart disease, heart attack, stroke, and premature death, if left untreated. First-degree relatives have a **50% chance** of having FH. More distant relatives are also at risk. If left untreated, people with FH have up to **20 times** the risk of developing premature heart disease. **Risk of premature death and cardiovascular events, such as heart attack and stroke, can be reduced by as much as 80% with early and aggressive lipid lowering therapy.**[1]

Your patient's relative received a positive result for FH through genetic testing via **DISCOVER-FH**, a federally funded grant through University of Texas Southwestern (UTSW). As FH is an inherited condition, **we are offering your patient both a lipid panel and genetic testing at no cost.**

We are providing you with this information as your patient is likely to want to discuss this with you as their trusted source of healthcare information.

The following pages will give you more information about the DISCOVER-FH program at UTSW. **Included with this information is your patient's relative's genetic testing lab report.**

We also strongly suggest that your patient has their **LDL-cholesterol checked, regardless of whether genetic testing is pursued.**

If you have any questions or concerns, please do not hesitate to contact us at **1 (xxx) xxx-xxxx** or.

Sincerely,

Zahid Ahmad, MD
Associate Professor of Medicine
UTSW
Principal Investigator, DISCOVER-FH
(xxx) xxx-xxxx | Zahid.ahmad@utsouthwestern.edu

[1] Versmissen J, Oosterveer DM, Yazdanpanah M, et al. Efficacy of statins in familial hypercholesterolaemia: a long term cohort study. *BMJ*. 2008;337:a2423. Published 2008 Nov 11. doi:10.1136/bmj.a242

Healthcare Professional FAQs

Can You Tell Me More About DISCOVER-FH?

DIrect SCreening Of RelatiVEs to Reveal FH (DISCOVER-FH)

DISCOVER-FH is a federally funded four-year grant. The goal of DISCOVER-FH is to increase the number of at-risk individuals who are screened, diagnosed, and referred for treatment of FH. This program is modeled after a successful program in Holland and has been adapted for the United States. UTSW has partnered with the Family Heart Foundation, a national non-profit, research and advocacy organization, to contact at-risk relatives throughout the US and arrange for their genetic and lipid testing. The Family Heart Foundation will return test results to at-risk relatives and if positive will explain the importance of treatment. Dr. Zahid Ahmad from UTSW and Dr. Mary McGowan from the Family Heart Foundation are available to answer questions you may have about lipid lowering therapies and if needed can recommend a lipid specialist in your area for consultation.

Can You Tell Me More About Genetic Testing Through This Program?

A genetic test is a clear way to determine if your patient has inherited FH.

Your patient's relative received their FH result from UTSW. UTSW is a hospital system in Texas. UTSW has partnered with name of lab, a nationwide laboratory, to provide genetic testing.

- Your patient is eligible for no cost genetic testing through name of lab for a limited time.

The genetic test through name of lab is performed on either saliva or blood.

- A member of the Family Heart Foundation will work with your patient to arrange for genetic testing.

The cost of your patient's Family Variant genetic test is covered by name of lab **if it is ordered by a member of the Family Heart Foundation team {End Date of 150-Day Window}**.

- Your patient and/or their insurance will be responsible for any potential costs associated with testing outside of this window or at a different laboratory.
- Your patient and/or their insurance will be responsible for any potential costs associated with visiting a healthcare professional.

Does My Patient Also Need Cholesterol Testing?

Yes, they do! A cholesterol panel that includes LDL-C can also help you determine if your patient has FH.

Regardless of whether your patient gets a genetic test, we strongly suggest that they have their cholesterol checked. A lipid panel is also covered by name of lab.

- A member of Family Heart Foundation can arrange for your patient to have a cholesterol panel that includes an LDL-C level drawn at a name of lab facility.
- A member of the Family Heart Foundation will call your patient to review the results of their cholesterol panel
- If your patient is diagnosed with FH, cholesterol lowering medications will likely be required.

Follow-up cholesterol testing and visits with a healthcare professional will not be covered by this program.

- Your patient and/or their insurance will be responsible for any potential costs associated with follow-up cholesterol test or visits with a healthcare professional.

What If I Have Questions About FH Or This Program?

It is important to understand this information and why this is so important for your patient and their family. We are here to help!

The **UTSW Team** is here to help provide more information about FH and answer your questions about this program.

Email
Zahid.ahmad@utsouthwestern.edu

Phone
1 (xxx) xxx-xxxx

DISCOVER FH Webpage

The **FH Foundation** is a patient-centered organization that can help answer your questions about FH and provide support for you and your patient.

Email
info@theFHfoundation.org

Phone
1 (626) 583-4674

Website
theFHfoundation.org

POSITIVE Results Letter to Relative-

Dear _____,

Thank you for taking part in this Research Program involving Cascade Family Screening to Find Familial Hypercholesterolemia (FH).

It was a pleasure working with you to help arrange your screening for FH. This letter is for your records, and it summarizes the results of your screening. A copy of your test results is included, and you are encouraged to share this with your health care provider.

Summary:

Based on your ***screening results, personal history, and family history, it is **probable** that you have familial hypercholesterolemia. It is important that you speak with your health care provider about these results. Early treatment with cholesterol lowering medications are available and they will help lower your risk for heart disease and stroke.

It is known that individuals with FH, if left untreated are at a greater risk for heart attack and stroke.

Lab Results:***
Medications: ***
Personal History: ***
Family History: ***

About Familial Hypercholesterolemia:

Familial hypercholesterolemia (FH) is a common genetic condition that causes very high low density lipoprotein (LDL) cholesterol or "bad cholesterol". FH is inherited, meaning it is passed down from parents to children.

Next Steps:

It is important to speak with your health care provider about these results.
There are a number of FH specialists who you might consider seeing as well.
An FH specialist will be able to work with you to determine the right treatment plan for you. The Research Team is here to answer your questions and can help you find an FH specialist if needed.

General Treatments Goals for FH:

For people with FH but no history of heart disease or stroke, the goal LDL-C is less than 100 mg/dL.
For people with FH who have already developed heart disease or stroke, the goal is an LDL-C of less than 70 mg/dL. Recent recommendations for LDL-C are pushing for less than 55 mg/dL in higher risk people. In general, the lower the LDL level the better.

For family members:

Because you likely have FH, your family members are also at risk of having FH. Close family members (parents, siblings, and children) all have a 50% chance of having FH and should consider screening. If your relatives need help finding screening, we are happy to help them with this.

Staying Healthy

In addition to maintaining an acceptable level of blood cholesterol through the use of cholesterol lowering medication you can help lower your risk of heart disease and other conditions by following a healthy diet, engaging in exercise regularly, maintaining healthy levels of blood sugar and blood pressure, not smoking, and keeping your weight in a healthy range. Your health care provider can provide you with more guidance on these lifestyle measures.

Resources:
FamilyHeart.org
Others?

Sincerely
***
Contact Info

Genotype(+), Phenotype(-) Results Letter to Relative-

Dear _____,

Thank you for taking part in this Research Program involving Cascade Family Screening to Find Familial Hypercholesterolemia (FH).

It was a pleasure working with you to help arrange your screening for FH. This letter is for your records, and it summarizes the results of your screening. A copy of your test results are included, and you are encouraged to share this with your health care provider.

Summary:

Based on your genetic testing results
(screening results, personal history, and family history)- delete?
you have familial hypercholesterolemia. It is important you speak with your health care provider about these results. Your LDL-C is lower than we typically see with FH, but it still requires treatment. Treatment with cholesterol lowering medications will help lower your risk for heart disease and stroke.
It is known that individuals with FH, if left untreated are at a greater risk for heart attack and stroke.

Lab Results:***- (LDL-C less than 190 mg/dL)
Genetic testing- positive (state identified gene defect: LDLR, ApoB, PCSK9)
Medications: ***
Personal History: ***(no history of Cardiovascular disease)
Family History: *** (no history of early Cardiovascular disease in first degree relative)

About Familial Hypercholesterolemia:

Familial hypercholesterolemia (FH) is a common genetic condition that typically causes very high low density lipoprotein (LDL-C) cholesterol or "bad cholesterol". FH is inherited, meaning it is passed down from parents to children. Even though your LDL-C level is lower than what is seen in FH, your family members may still have a very elevated level.

Next Steps:

It is important to speak with your health care provider about these results.
There are a number of FH specialists who you might consider seeing as well.
An FH specialist will be able to work with you to determine the right treatment plan for you. The Research Team is here to answer your questions and can help you find an FH specialist if needed.

General Treatments Goals for FH:

For people with FH with no history of heart disease or stroke, the goal LDL-C is less than 100 mg/dL.
For people with FH who have heart disease or stroke, the goal is an LDL-C of less than 70 mg/dL. Recent recommendation for LDL-C is less than 55 mg/dL in higher risk people.
In general, the lower the LDL level the better.

For family members:

Because you have FH, your family members are also at risk of having FH. Close family members (parents, siblings, and children) all have a 50% chance of having FH and should consider screening. If your relatives need help finding screening, we are happy to help them with this.

Staying Healthy

In addition to maintaining an acceptable level of blood cholesterol through the use of cholesterol lowering medication
you can help lower your risk of heart disease and other conditions by following a healthy diet, engaging in exercise regularly, maintaining healthy levels of blood sugar and blood pressure, not smoking, and keeping your weight in a healthy range. Your health care provider can provide you with more guidance on these lifestyle measures.

Resources:
FamilyHeart.org
Others?

Sincerely
***
Contact Info