FH Canada: Increasing Awareness, Targeted Screening, Empowering Patients, Saving Lives

IAS - Pfizer IGLC Grant # 24038231 - **FINAL PROGRESS REPORT**

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Dr Gordon Francis, Healthy Heart Program Prevention Clinic, University of British Columbia, Vancouver, BC, Canada
Dr Brian McCrindle, The Hospital for Sick Children, University of Toronto, Toronto, ON, Canada
Dr James Brophy, Epidemiology and Biostatistics, McGill University, Montreal, QC, Canada

HF Canada Hypercholestérolémie Familiale FH Canada Familial Hypercholesterolemia

Purpose

The overall goal of the project was to increase awareness of Familial Hypercholesterolemia (FH) among health care professionals (HCP), their patients and family members through the creation of educational resources and web-based applications to simplify FH diagnosis and treatment.

The **3 principal objectives** of the proposal were to:

1- Increase awareness of FH among HCP in Canada;

2- Increase ease of diagnosis for family physicians and cascade screening through simplified Canada FH definition and apps;

3- Increase awareness of FH for Canadian patients and their family members.

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Methods/Results

We leveraged the FH Canada registry and its website (www.FHCanada.net) to participate in the:

1) Creation of educational resources for HCP across Canada:

- Accredited teaching slide kits including the latest knowledge on FH, bilingual and free on the FH Canada website;

- Peer-reviewed papers:

  - 2018 Update of the CCS Position Statement on FH to be published in the *Canadian Journal of Cardiology* Fall 2018;

  - New simplified Canadian definition of FH (submitted to the *Canadian Medical Association Journal*);

  - Summary paper on the Canadian experience with FH (submitted to *Atherosclerosis*).

- FH Network annual meetings: Montreal in 2016; Vancouver in 2017.

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New simplified Canadian definition of FH

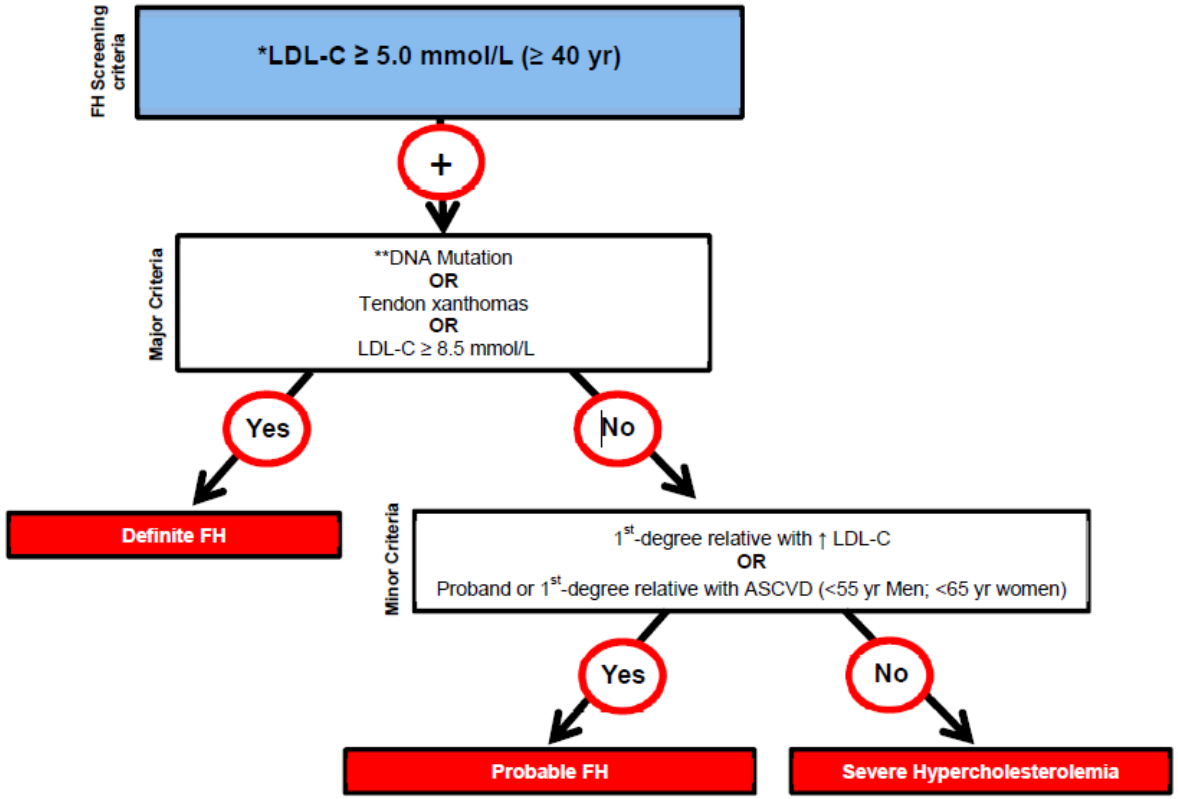

Figure 1. Canadian definition for the clinical diagnosis of FH.

* Secondary causes of high LDL-C should be ruled out (severe or untreated hypothyroidism, nephrotic syndrome, hepatic disease (biliary cirrhosis), medication especially antiretroviral agents);
LDL-C ≥ 4.0 mmol/L for age < 18 yr;
LDL-C ≥ 4.5 mmol/L for age ≥ 18 yr and < 40 yr.
** Causal DNA mutation refers to the presence of a known FH-causing variant in the *LDLR*, *APOB* or *PCSK9* gene based on presence of the variant in ClinVar, HGMD or WDLV databases, in the proband or a first-degree relative. FH diagnosis in a patient with a DNA mutation but normal LDL-C levels is unclear. Yearly follow-up of the proband is suggested and cascade screening of family members should be initiated. Note: In any case, cascade screening should be implemented; treatment decision should be at the discretion of the treating physician.

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Past Annual Meetings on FH

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FH Canada invites you to

Familial Hypercholesterolemia Canada Network

Conferences will be given in French; Q&A in French and English

Friday, October 21st, 2016

12:00-13:00	Registration	
13:00-13:40	Introduction, FH Canada Registry	*Dr Jacques Genest*
13:40-14:20	Definition of FH, Genetics of FH	*Dr Daniel Gaudet*
14:20-15:00	2016 Canadian Guidelines on CVD Prevention and Treatment of FH	*Dr Jean Grégoire*
15:00-15:40	Treatment of FH	*Dr Robert Dufour*
15:40-16:00	Discussion/Questions & Answers	
16:00-17:00	Break, Informal discussions, Booths	
17:00-19:00	Public Advocacy Forum *Patients' testimonies and discussions with GPs*	

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Please R.S.V.P. (www.fhcanada.net)

Centre universitaire de santé McGill – Institut de recherche | McGill University Health Centre – Research Institute

CCRN Canadian Collaborative Research Network

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Familial Hypercholesterolemia: How to Recognize and Manage Patients in Your Practice?

REGISTRATION

Early bird: $50.00
Valid until September 20 2017

$75 starting September 21
Registration closes: October 18 2017.

Please R.S.V.P. at www.ccrnmd.com

Friday, October 20, 2017
12:00-6:30 pm

St. Paul's Hospital,
1081 Burrard Street, Vancouver, BC, V6Z 1Y6
The Cullen Family Lecture Theatre, Room 1477,
Providence, Level 1

CHAIR

Liam R. Brunham,
MD, PhD, FRCPC, FACP
Assistant Professor of Medicine, University of British Columbia
Scientist, UBC Centre for Heart Lung Innovation
Physician, Healthy Heart Program Prevention Clinic, St. Paul's Hospital
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Clinical teaching instructor, Department of Family Medicine, University of British Columbia,
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AGENDA

12:00 p.m.	**Registration / Lunch**	
1:00 p.m.	***Intro, Landscape of FH in Canada - role of FH registry***	Dr. Liam R. Brunham
1:20 p.m.	***Genetics of FH and role of genetic testing***	Dr. Jacques Genest
1:40 p.m.	***How to recognize and diagnose FH***	Dr. Gordon Francis
2:00 p.m.	**Q&A**	All faculty
2:20 p.m.	**Break**	
2:40 p.m.	***Treatment of FH including new and emerging therapies***	Dr. John Mancini
3:00 p.m.	***International Perspectives on FH***	Dr. Joshua Knowles
3:40 p.m.	**Discussion/Questions & Answers**	All speakers
4:00 p.m.	**Break, Informal discussions, Booths, Nutrition**	
4:30 p.m.	***Patient Forum: Patients' stories and discussions with medical doctors***	
6:30 p.m.	**Close**	

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Methods/Results

2) Design of specific apps for a simplified FH diagnosis:

- We validated a simplified FH diagnosis based on the Simon-Broome criteria but adapted for Canada (paper submitted to *CMAJ*).

- We validated, in the Canadian population, an algorithm to impute baseline LDL-C from values obtained while on lipid-lowering therapy. This tool is useful for assessing the degree of severity of FH for new patients. Published in *Clinical Chemistry* 2017;64(2):355-362. PMID: 29038147.

- We participated in the creation of an app for the new Canadian definition of FH: The FH Calculator, including the imputation of baseline LDL-C. The app is bilingual, and freely downloadable (android or iPhone/iOS platforms), http://www.circl.ubc.ca/cardiorisk-calculator.html.

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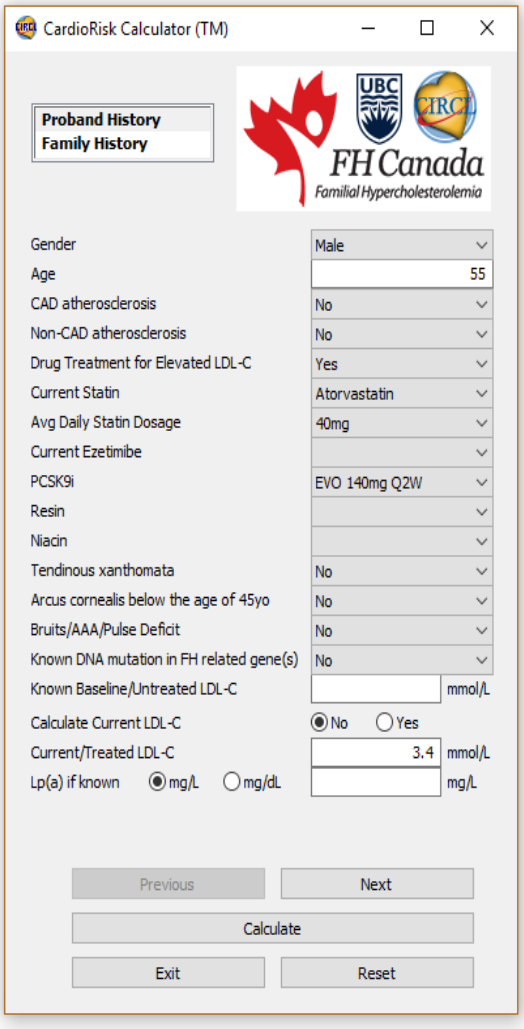

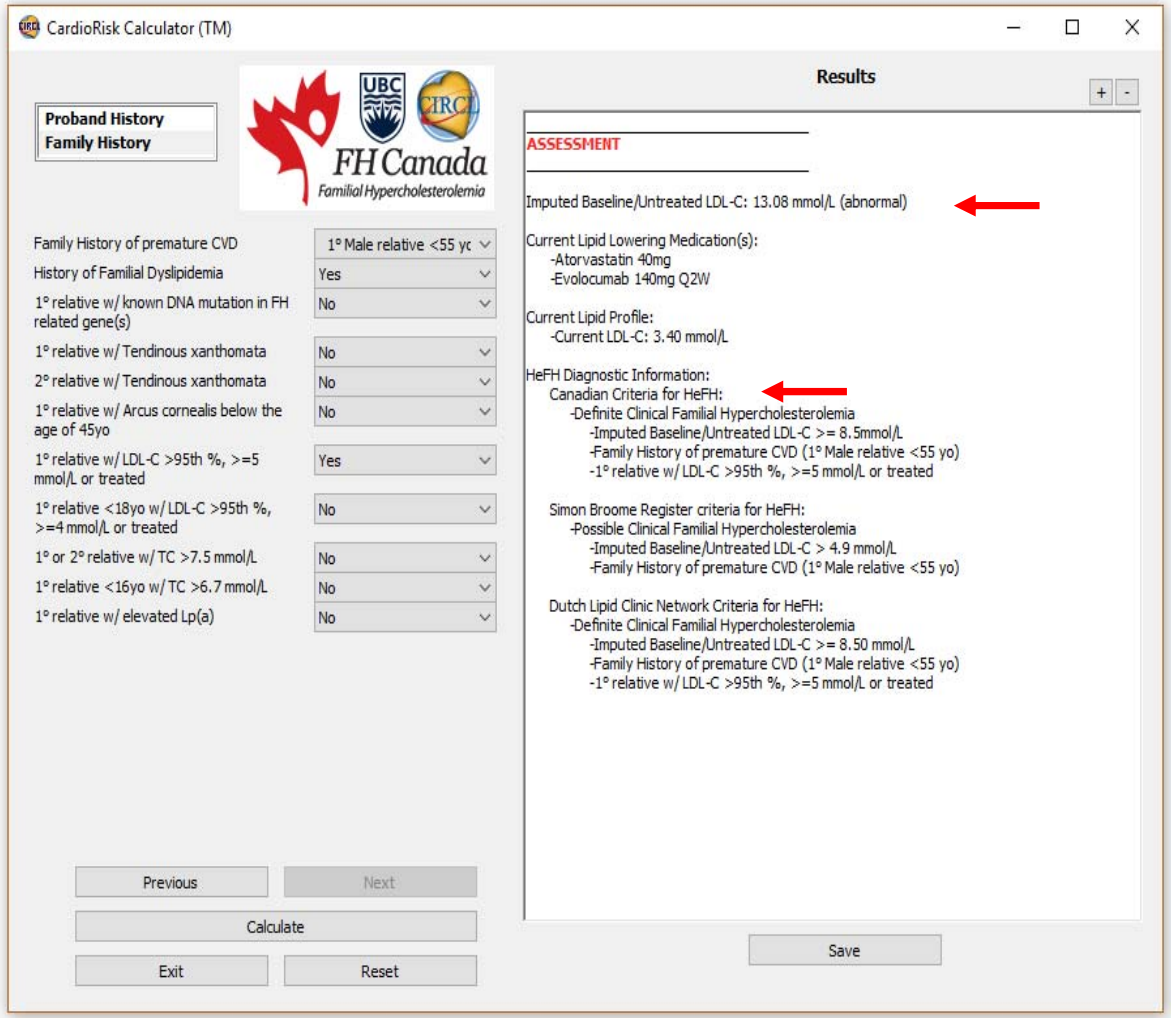

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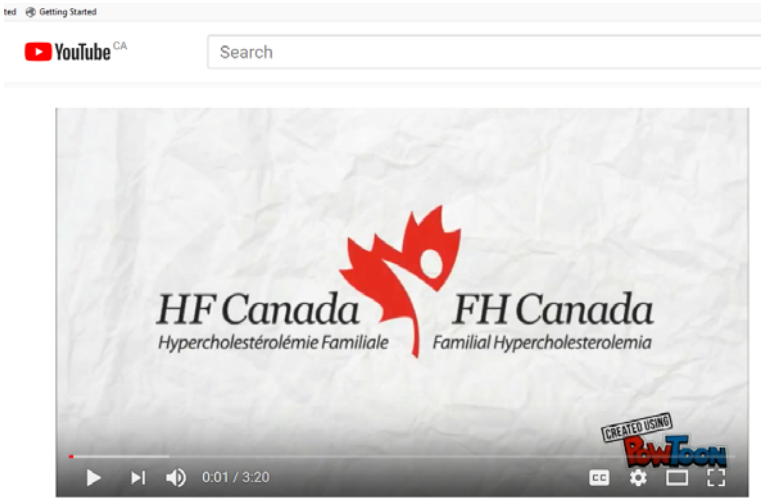
Methods/Results

3) Creation of educational FH Canada-based resources for patients:

- A patient brochure on FH and on the FH Canada registry.
- A presentation on how to easily draw a family tree (pedigree) and assess a pattern in high LDL-C and FH among family members.
- Educational videos on the genetic basis of FH and its clinical diagnosis, in lay language.
- Update of both versions of the FH Canada website i.e. patient and HCP, with new resources.



FH Canada - What is Familial Hypercholesterolemia?

www.fhcanada.net

Conclusion:

We successfully created resources to improve the precision of FH diagnosis, increase the number of diagnosed FH patients and family members and provide them access to expert care, on-going clinical trials and novel therapies. Now implemented, these interventions will directly improve the care of Canadian FH patients, a population at high risk of cardiovascular events.

Acknowledgement:

We would like to thank the International Atherosclerosis Society and Pfizer for the IAS – Pfizer Independent Grants for Learning & Change (IGLC) Grant in Lipid Management in High-Risk Patients, which has permitted the creation of clinical tools to improve the diagnosis of FH and increase awareness of this disease.

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