



# CWHHA ATLAS

EPIDEMIOLOGY, DIAGNOSIS AND MANAGEMENT OF CARDIOVASCULAR DISEASES IN WOMEN

## CHAPTER 3: PATIENT PERSPECTIVES

*Women with Experience Living with Cardiovascular Disease*

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# WELCOME HOUSEKEEPING



## **Sound and Video Quality Issues**

Click on link below the webinar window to open Zoom



## **Chat Box**

Ask questions or if you are in need of technical support.



## **Q & A**

To ask questions through session.



## **Recording**

Will be available on the CWHHA.ca website.



## **Evaluation**

Please complete the evaluation form after the session.

# Disclosure Statement

**We do not have any affiliations (financial or otherwise) with a commercial organization that may have a direct or indirect connection to the content of our presentations.**

# Disclaimer

We cannot provide specific advice on individual medical problems.

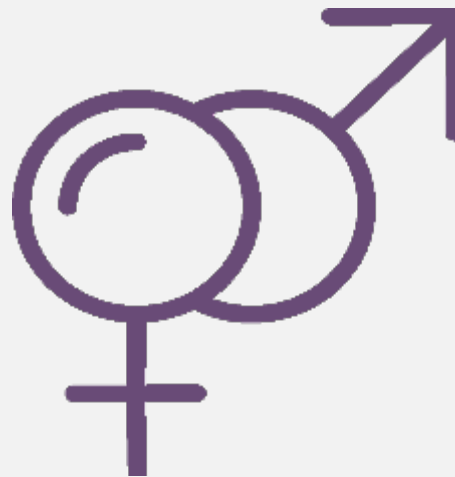
Today, we are not discussing specific cardiovascular diseases.

The focus is on the context of the patient's experience with cardiovascular disease in the general sense of accessing care, and challenges and tools in coping with a new diagnosis, (and hopefully eventually thriving again in the "new normal")!

# Learning Objectives

At the end of this webinar, you will be able to:

- Describe the **Canadian Women's Health Alliance**.
- Describe the **experience of a woman** living with cardiovascular disease.
- Identify the **barriers to accessing** acute cardiovascular care.
- List the **action items** to “open the gate” to women.
- Identify what patients can do to **participate more fully** in one's **care and recovery**.



# Polling Question

Who is in the audience today?

**A**

Person with  
lived  
experience /  
patient

**B**

Caregiver

**C**

Healthcare  
professional

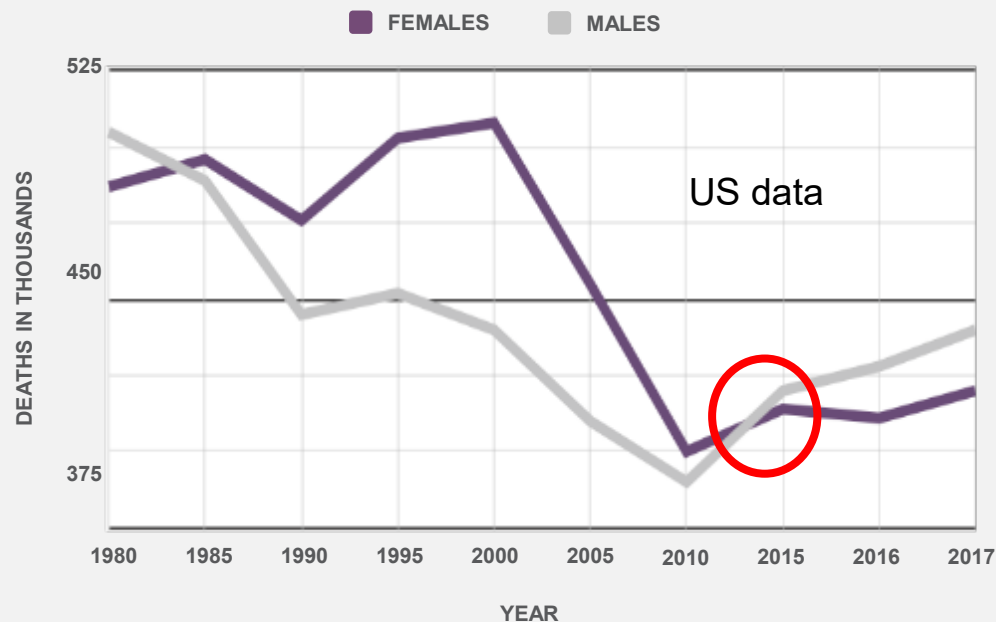
**D**

Researcher

**E**

Other

# Cardiovascular Disease in Women

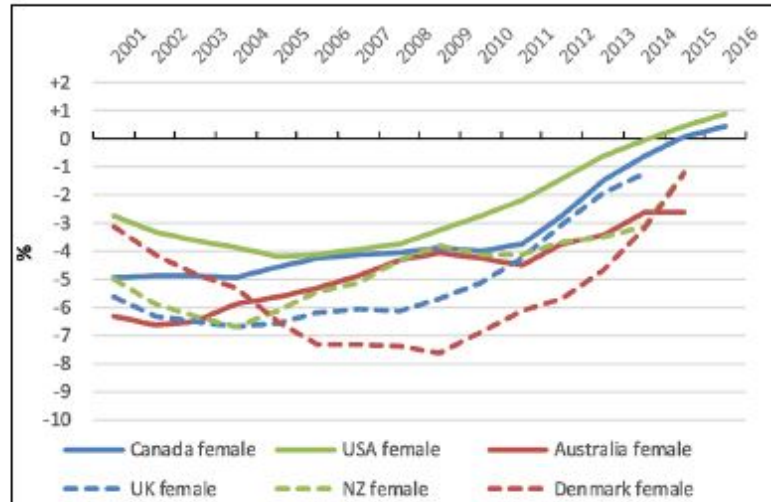


Cardiovascular disease is also a **leading cause of death** in women in Canada

Major advances in prevention, diagnosis, treatment and overall CV mortality for women in the past 2 decades, ...but recently losing ground...

Wenger, N. JACC 2021. 3;4:701-703

# In high-income regions, the decline in CVD mortality has slowed and CVD mortality has increased in women from certain countries



An analysis of the WHO Mortality Database found an increase of age-standardized cardiovascular disease death (35–74 years) during recent years in women in the USA and Canada.



The Lancet Clinical Commission  
on Cardiovascular Disease  
in Women

Lopez AD et al., Int J Epidemiol 2019

Adapted from Dr. R. Mehran, ACC2021



THE LANCET

# Canadian Women's Heart Health Alliance



## LAUNCHED IN 2018

**OUR VISION:** To improve women's cardiovascular health across the life span.

**OUR MISSION:** To support clinicians, scientists, patients, and decision-makers in working collaboratively to implement evidence, transforming clinical practices, and impacting public policy related to women's cardiovascular health.

## Pillars:

- Knowledge Translation and Mobilization
- Education & Training
- Advocacy
- Health Systems & Policy

# Executive Steering Committee (2021 – 2023)



**Thais Coutinho, MD**  
Executive Steering  
Committee Chair  
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**Najah Adreak, MD**  
Trainee Representative (2021 –  
2022)  
Vancouver, BC



**Bob Reid, PhD, MBA**  
Executive Steering Committee Vice  
Chair  
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COMMITTEE**

**SECRETARIAT  
(CWHHC)**

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Mullen, PhD**  
Director, CWHHC



**Lisa Comber,  
KTPC, BA**  
Lead, CWHHA



**Anice Wong,  
BFA**  
Project  
Coordinator,  
CWHHA



**Melissa Core-  
Gunn, BSc, DIPM**  
Communications

### KNOWLEDGE TRANSLATION AND MOBILIZATION



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Patient Advocate  
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Healthcare Professional  
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**Judy Luu,  
MD/PhD, FRCPC**  
Healthcare Professional  
Co-Chair  
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**Nicole Nickerson**  
Patient Advocate  
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**Kara Nerenberg,  
MD, MSc**  
Healthcare Professional  
Co-Chair  
Calgary, AB

# ADVOCACY WORKING GROUP



**HER  
HEART  
MATTERS**

WEAR RED CANADA • FEB 13



CANADIAN WOMEN'S  
HEART HEALTH CENTRE

NATIONAL  
ALLIANCE

CWHHA.CA | @CWHHAlliance

ON **FEBRUARY 13TH**, JOIN US TO RAISE  
AWARENESS ABOUT WOMEN'S HEART HEALTH.



**Attend or host an event  
in your community**



**Wear  
Red**

**SPREAD THE WORD USING:**

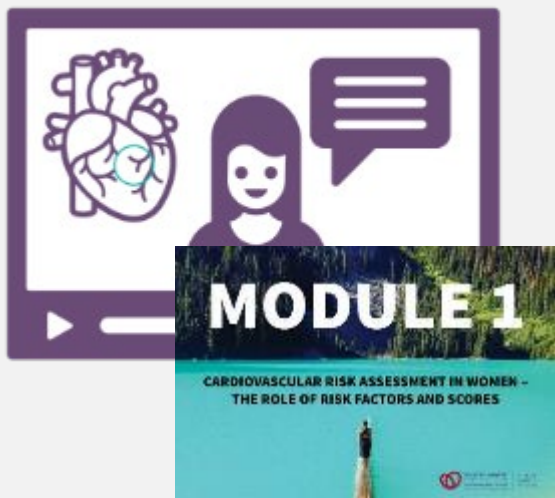
**#HERHEARTMATTERS**



**WEARREDCANADA.CA**



# TRAINING AND EDUCATION WORKING GROUP



## Canadian Women's Heart Health Education Course + Teaching Toolkit

**Target Audience:** Healthcare professionals and trainees within emergency medicine, general internal medicine and cardiology

**9 accredited modules:**

1. Cardiovascular **Risk Assessment** in Women – The Role of **Risk Factors** and Scores
2. **Acute Coronary Syndromes (ACS)** in Women
3. Approaches to **Chest Pain** - A **Sex & Gender** Focus
4. MI with Non-Obstructive Coronary Arteries (**MINOCA**)
5. Spontaneous Coronary Artery Dissection (**SCAD**)
6. Stress-Induced Cardiomyopathy (**SIC**)
7. Contemporary Management of Women with **Heart Failure**
8. Cardiovascular Risk In Women With **Gestational Diabetes & Hypertensive Disorders** Of Pregnancy
9. Recovery and **Cardiac Rehabilitation (CR)** for Women



**KNOWLEDGE TRANSLATION  
AND MOBILIZATION  
WORKING GROUP**

**HEALTH SYSTEMS  
AND POLICY  
WORKING GROUP**

***Consensus  
document***



***Policy  
document***

# Knowledge Translation and Mobilization + Health Systems and Policy Working Groups

*Published Manuscript GoRed Issue Feb 2020*

**Journal of the American Heart Association**

Volume 9, Issue 4, 18 February 2020

<https://doi.org/10.1161/JAHA.119.015634>



**GO RED FOR WOMEN SPOTLIGHT - CONTEMPORARY REVIEWCONTEMPORARY REVIEW**

## State of the Science in Women's Cardiovascular Disease: A Canadian Perspective on the Influence of Sex and Gender

Norris CM.....Mulvagh SL. J Am Heart Assoc 2020;9 (4)

**CWHHA.CA | @CWHHAlliance**



**NATIONAL ALLIANCE**

# CANADIAN WOMEN'S HEART HEALTH ALLIANCE **ATLAS**

## Epidemiology, Diagnosis, and Management of Cardiovascular Diseases in Women



- 9 unique “chapters”
- CJC Open
- Editor: Dr. M. Graham
- All 9 to be submitted by Dec. 2021
- 1<sup>st</sup>: published April 2020
- 2<sup>nd</sup>, 3<sup>rd</sup>: published
- 4<sup>th</sup>: in review
- 5<sup>th</sup> and 6<sup>th</sup>: to be submitted shortly
- 7<sup>th</sup>, 8<sup>th</sup> and 9<sup>th</sup> yet to be started
- Annual chapter updates
- “living document”

Norris CM ..... Mulvagh SL. CJC Open 2020

CWHHA.CA | @CWHHAlliance

REVIEW CANADIAN WOMEN'S HEART HEALTH ALLIANCE | [VOLUME 3, ISSUE 3](#),  
P229-235, MARCH 01, 2021



PDF [577 K]

# The Canadian Women's Heart Health Alliance Atlas on the Epidemiology, Diagnosis, and Management of Cardiovascular Disease in Women—Chapter 3: Patient Perspectives

[Tracey J.F. Colella, RN, PhD](#) • [Marsha Hardy, MSW, RSW](#) • [Donna Hart](#) •

[Jennifer A.D. Price, PhD, RN, CCN\(C\)](#) • [Hope Sarfi](#) • [Kerri-Anne Mullen, PhD, MSc](#) •

[Sharon Mulvagh, MD, FRCPC, FACC, FASE, FAHA](#) •

[Colleen M. Norris, PhD, GNP, MSc, BScN, FAHA, FCAHS](#)   • [Show less](#)

[Open Access](#) • Published: February 10, 2021 • DOI: <https://doi.org/10.1016/j.cjco.2020.11.020> •





## CHAPTER 3 | PATIENT PERSPECTIVES

### EXPERIENCING AND LIVING WITH CVD AS A WOMAN

The unique, yet common, challenges of women living with CVD.

**Misunderstood,  
misinterpreted,  
misdiagnosed,  
and mistreated  
= BIG MISTAKE**



### ACTION ITEMS TO 'OPEN THE GATE' TO WOMEN: WHAT OUR PATIENTS WANT AND NEED

**Primary Care Environments:** Improve survival and recovery rates for women by establishing clinical diagnostic protocols.

**Institutional Environments:** Reinforce cardiac rehab, physical and psychosocial, as part of the healing process.

**Educational Environments:** Health care professionals to be trained to understand women's cardiovascular health.

**Research Environments:** Include greater representation of women in research.

**Policy Environments:** Public health awareness of CVD risk for all women.

**What Patients Can Do:** Take charge of your health and advocate to share your experiences.

# Experience Living with Heart Disease



CANADIAN WOMEN'S  
HEART HEALTH CENTRE

NATIONAL  
ALLIANCE



*Hope's Story*

# *My Recovery...*



Better eating



Physical activity



Cardiac rehabilitation  
and  
peer support programs



Online  
community and  
support groups

# *What am I doing now...*



## Advocating for Women's Heart Health

- Participated in the first 2016 Canadian Women's Heart Health Summit
- Media interviews sharing my story
- Member of the Canadian Women's Heart Health Alliance
- Member of the West Regional Planning Committee for Wear Red Canada - Feb. 13

*“Women patients share with us that the aftermath of a CVD event is both **daunting and stressful** and constitutes a **complete life change**.*

*Even after **years** of living with heart disease, **concern** regarding the risk of having a **recurrent event** is **always present**.”*

# Experiencing & Living with CVD as a Woman

## UNIQUE PROFILE

- Traditional risk factors = greater morbidity/mortality impact
- Race and ethnicity - more severe impact of risk factors
- Poorer outcomes in 1-year following event



## UNIQUE EXPERIENCES

- Lower degree of perceived health
- Higher levels - fear, anxiety, depression & stress
- Partner relationship & intimacy
- Social roles - family context
- Peer support & shared lived experience

# Polling Question

Which of the following statements is true?

The majority of Canadian women identify diabetes and high blood pressure as risk factors for heart disease.

**A**

Awareness of risk factors for heart disease has increased significantly among ethnically diverse women.

**C**

Fewer than 50% of Canadian women identify smoking as a risk factor for heart disease.

**B**

Younger women (age 25-34 yrs) report the highest level of awareness of postpartum risk factors for heart disease.

**D**

# Polling Question

Which of the following statements is true?

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**B**

Younger women (age 25-34 yrs) report the highest level of awareness of postpartum risk factors for heart disease.

**D**

# Targeting Knowledge Gaps & Inequities

*Canadian Journal of Cardiology 30 (2014) 837–839*

## Clinical Research

### Perceived vs Actual Knowledge and Risk of Heart Disease in Women: Findings From a Canadian Survey on Heart Health Awareness, Attitudes, and Lifestyle

Lisa A. McDonnell, MSc, MBA, Andrew L. Pipe, MD, Courtney Westcott, MSc, Sue Perron, BEPS, Deborah Younger-Lewis, RN, BScN, Nadine Elias, BSc, Jessica Nooyen, MHK, and Robert D. Reid, PhD, MBA

*Division of Prevention and Rehabilitation, University of Ottawa Heart Institute, Ottawa, Ontario, Canada*

“What are **possible symptoms** of heart disease that a woman might experience?”

FIGURE: Knowledge of heart disease symptoms.

CHEST PAIN

43%

SHORTNESS OF  
BREATH ON EXERCISE

38%

PAIN SPREADING TO  
SHOULDERS, NECK, ARM

29%

UNUSUAL FATIGUE

21%

LIGHT HEADEDNESS/  
DIZZINESS

16%

NAUSEA

15%

% OF WOMEN IDENTIFYING SYMPTOM

# Targeting Knowledge Gaps & Inequities

## Circulation

### AHA SPECIAL REPORT

Ten-Year Differences in Women's Awareness  
Related to Coronary Heart Disease: Results of the  
2019 American Heart Association National Survey  
A Special Report From the American Heart Association

Journal of Cardiovascular Nursing  
Vol. 35, No. 1, pp. 6-7 | Copyright © 2021 Wolters Kluwer Health, Inc. All rights reserved.



## Progress in Prevention

### Women's Awareness of Heart Disease and Risk Two Steps Forward and One Step Back

Lola A. Coke, PhD, ACNS-BC, FAHA, FPCNA, FAAN  
Laura L. Hayman, PhD, MSN, FAAN, FAHA, FPCNA

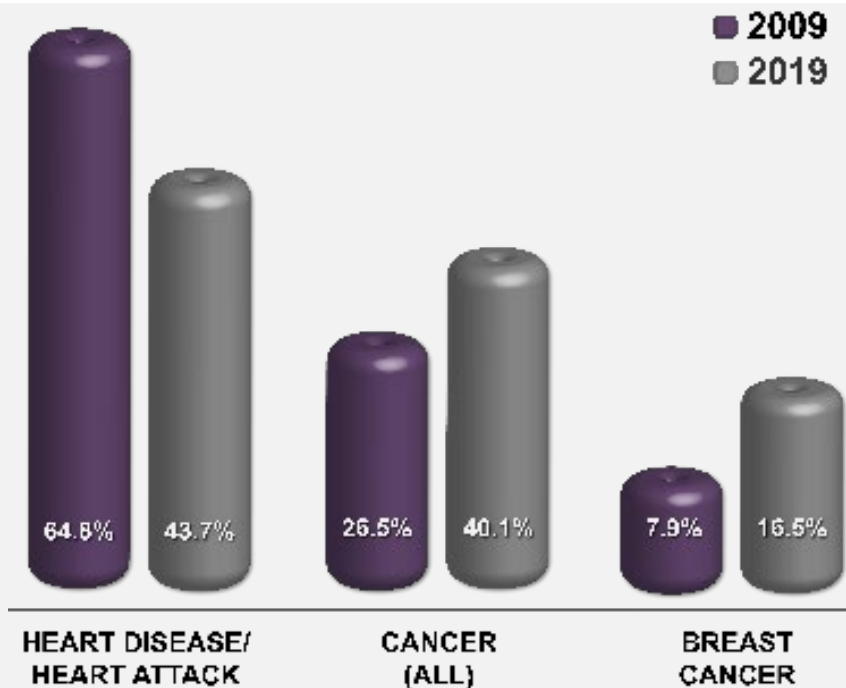


FIGURE: Proportion of US women identifying heart disease/ heart attack, cancer (all), or breast cancer as the leading cause of death among women: 2009 vs 2019. All values between 2009 and 2019,  $P < 0.05$

# Targeting Knowledge Gaps & Inequities



American Heart Association®



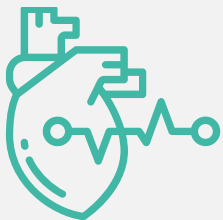
Yet a lack of awareness persists among the lay public and health care professionals...

# “Stopped at the Gate” - Barriers to Access



## Lack of Suspicion/Diagnosis/Misdiagnosis

- Multifactorial sex-specific issues → variation in symptom profile
- Traditional risk stratification tools = under-recognition - misdiagnosis



## Access to Acute Cardiovascular Care

- Early heart attack symptoms missed in 53% of all women seen in ED (HSFC, 2018)
- Fewer classic symptoms of chest pain



## Standard of Care Time Frames

- Target benchmarks not achieved



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**Educational Environments:** Health care professionals to be trained to understand women's cardiovascular health.

**Research Environments:** Include greater representation of women in research.

**Policy Environments:** Public health awareness of CVD risk for all women.

**What Patients Can Do:** Take charge of your health and advocate to share your experiences.



# Actions to “Open the Gate” to Women



## Primary Care & Educational Environments

- Address unconscious bias - procedural changes/checklists
- Sex & gender specific clinical diagnostic protocols, testing protocols
- Provider awareness - referral to cardiac rehabilitation



## Institutional Environments

- Care pathways
- Peer support
- Create culture for patient perspectives and support

# Actions to “Open the Gate” to Women



## Educational

- Sex/gender-based differences core medical education curriculum
- Allied health professionals
- Continuing education & competency training

## Research

- Standardized reporting sex/gender disaggregated data
- Design and tools

## Policy

- Government support & mass public awareness of CVD risk
  - diversity of women
- Targeted early risk factor awareness

# What Patients Want and Need

What can we do to more fully participate in our care and recovery:

**Attend Recommended Programming**

- Cardiac Rehabilitation
- Education
- Peer Support

**Get Involved in Research**

- As a Participant
- Patient Partner/Investigator
- Be Curious

**Become More Aware & Educated**

- One's diagnosis & Recovery
- Signs & Symptom Recognition
- Understanding our Own Risk Profile

**Become an Advocate**

- Self-Advocacy - Champion for our Health
- Advocate for Others - Share our Stories/Recoveries
- Peer Support

# In Summary...



- Significant strides in the **awareness of sex and gender differences** for women living with CVD
  - Diagnosis, treatment, management & rehabilitation
- However, there is **much work yet to be done**
- The lived experience of women is key to **understanding the journey** & facilitating change
- Critical need for **sex and gender-specific strategies** at **all levels** of the health care system
  - Education, awareness, clinical diagnostic protocols
  - Supportive structures to reduce barriers - “Stopped at the Gate”
  - Ensure we collectively “Open to Gate” to Women
- Continued diligence and advocacy to **improve outcomes for women.**

# We want to hear from you.

## Questions, Comments...

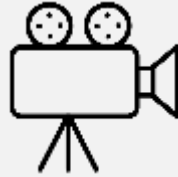


# Programs and Resources

- [CWHHA ATLAS Chapter 3 Publication](#)
- [CWHHA ATLAS Chapter 3 Infographic](#)
- [Heart & Stroke 2018 Ms. Understood Report](#)
- [Canadian Women's Heart Health Centre, Women @ Heart program](#)
- [Women with Heart Online | Cardiac College](#)
- [Cardiac College](#)
- [Heartlife Canada](#)
- [Heart & Stroke, Community of Survivors](#)
- [Heart & Stroke, Canadian Women with Medical Heart Issues](#)
- [SCAD Alliance, Connect for Support](#)
- [Additional infographics from the Canadian Women's Heart Health Centre](#)
- How can you become an advocate? [Wear Red Canada](#), [CWHHC Community Advocate Toolkit](#), [Join the CWHHA](#)

**Visit CWHHA.ca for more information.**

# THANK YOU!



## Recording

Will be available on the CWHHA.ca website.



## Evaluation

Please complete the evaluation form after the session.



## Questions

Email us at [cwhhc@ottawaheart.ca](mailto:cwhhc@ottawaheart.ca).

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The University of Ottawa Heart Institute is the convening body of the Canadian Women's Heart Health Alliance, which is a network of experts and advocates from across Canada aiming to improve women's cardiovascular health across the lifespan.

POWERED BY:



CANADIAN WOMEN'S  
HEART HEALTH CENTRE  
CENTRE CANADIEN DE SANTÉ  
CARDIAQUE POUR LES FEMMES

Visit [CWHHA.ca](http://CWHHA.ca) for more information.