

# Fontan and Research: how you or your family can participate?

Dr Jasmine Grewal & Kristina McGuire

# Why Participate in Research?

- Care provider perspective:
  - Positive feeling of helping others
  - Transfer of knowledge
    - Teaching others
  - Contributing to advancing the science
- Perspective of someone with Fontan or with a Fontan patient in the family:
  - Gain information on Fontan-safe lifestyles
  - Passing on unique knowledge of your lived experience with Fontan

# What Research Needs to be Done?

- Information for teachers/schools
- Cardiac Rehabilitation
- How to cope with challenges
- Knowledge mobilization necessary to 'spread' research findings
  - Sharing results in an understandable format

## Barriers to Research?

- Physical or emotional
  - Difficult to discuss 'hard times'
- Feel they may not have the expertise to participate

## Overcoming Barriers:

- Make people feel supported
- Make it ease to consent and participate