

# **How Patients and Families Can Improve Adult Congenital Heart Care**

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*God Helps Those Who Help Themselves*

“ACHD Patient and Provider Partnership Proves Particularly Potent”

## **The Politics of ACHD Care in Canada**

- ♥ Toronto General Hospital
- ♥ Cardiology
- ♥ Cardiac surgery
- ♥ The Administration
- ♥ The Board
- ♥ The Heart & Stroke Foundation
  - Very influential if they want to be
  - Don't hesitate to mention CHD in fundraising
  - Have never helped improve ACHD in Ontario
- ♥ The Ontario Ministry of Health
  - Been there many times
  - Cardiac Care Network – not responsible
  - Bureaucrats – experts in obstruction & delay

## **How Do ACHD Patients Pay?**

- ♥ Surgical delays
- ♥ 24-100 weeks for CHD surgery!!
- ♥ 3 weeks for coronary surgery
- ♥ Heart cath delays
- ♥ ASD device insertion 100 weeks!!
- ♥ Appointment delays for semi-urgent matters

- ♥ Care not comprehensive
- ♥ Patients not educated
- ♥ No transition process from pediatric care
- ♥ Waiting Lists are Too Long
  - **Because there is no plan**

### **Greater Coordination Between Pediatric and Adult Congenital Heart Services**

- ♥ An ACHD Plan is Needed in Ontario, and the Regions of Canada
- ♥ An ACHD Plan is needed in Canada and its Regions
  - **and it won't happen without patient leadership!**

### **What Can You Do to Help Yourselves?**

- ♥ Become politically active and effective
- ♥ Lead the political process
  - We will help you and support you
- ♥ Patient and Family Political Action
- ♥ Governments
- ♥ Ontario
- ♥ Other provinces
- ♥ Federal
  - Be savvy and persistent

### **Patient and Family Political Action**

- ♥ Hospitals
- ♥ Toronto General Hospital
- ♥ Hospital for Sick Children
  - Others – London, Hamilton

♥ Heart and Stroke Foundations

- Ontario
- Alberta
- Canada

♥ Transition process for adolescents

♥ Patient prepared to take knowledgeable control

♥ Individual education and motivation

♥ Orderly and appropriate transfer of care from pediatric to adult providers

♥ Partnerships between patients/families and health care communities

♥ Better research on which to base treatments

♥ Faster service

♥ More comprehensive services

**High-quality ACHD care:**

- ♥ Is critically important
- ♥ Must be carefully developed
- ♥ Cannot be taken for granted

**Summary**

What happens regarding ACHD care is dependent on both:

- ♥ The health care professionals
- ♥ The patients and families
  - The political power lies with you, the patients and families

You need to develop the capability of effectively and persistently representing your interests to:

- ♥ The ACHD clinic
- ♥ The hospital
- ♥ The government