



Canadian Congenital Heart Alliance

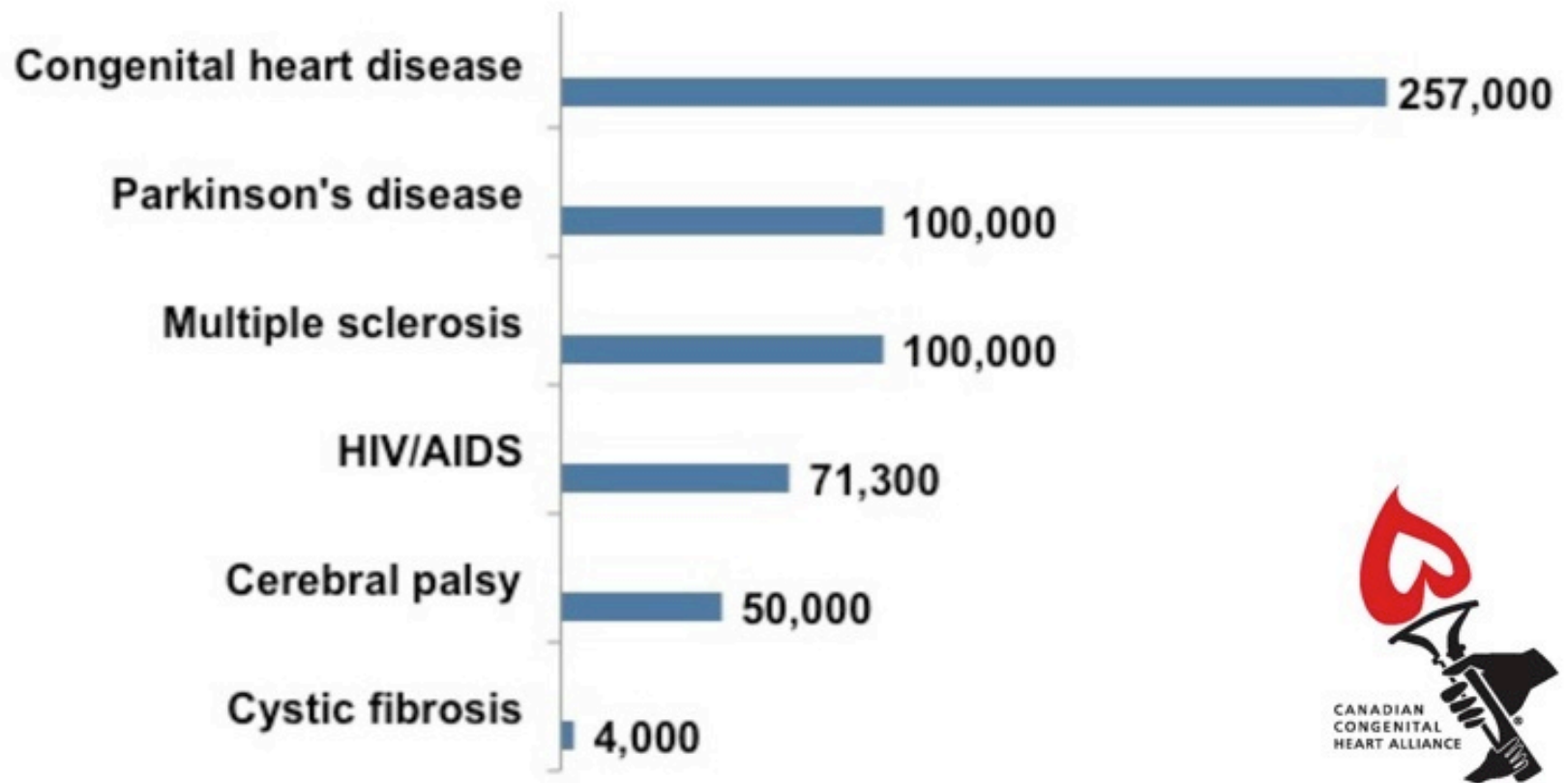
We're here for you!



CHD - Background

- Canada historically a leader in CHD research and care
- Toronto's ACHD clinic opened in 1959 – first *worldwide*
- CCS 1996 Guidelines for ACHD care first, and influenced CHD care worldwide
- **CHD is unprecedented medical success story!**
 - 50 years ago most babies died in infancy/childhood

CANADIAN POPULATION DISEASE STATISTICS



Sources: Canadian Congenital Heart Alliance, Parkinson Society of Canada, Multiple Sclerosis Society of Canada, Public Health Agency of Canada, Active Living Alliance, Cystic Fibrosis Canada

of Canadians living with well known, long-term diseases



Congenital Heart Disease

Parkinson's

Multiple Sclerosis

Cystic Fibrosis

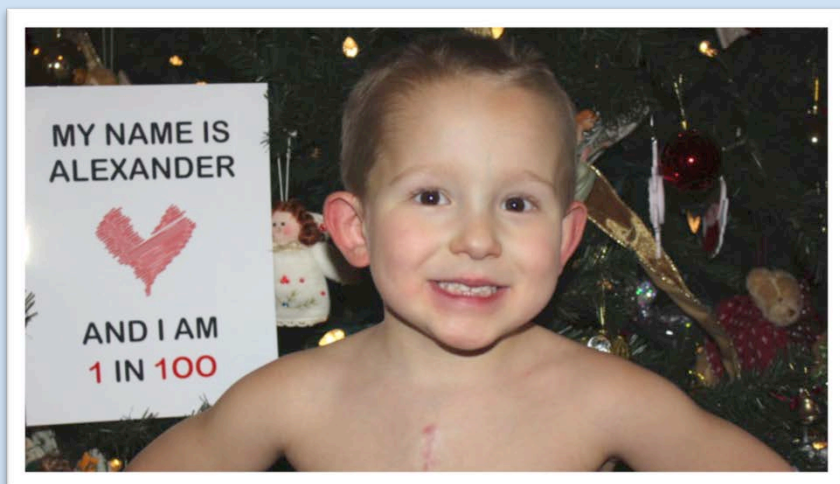
ALS



Andrew Redington, MD, FRCP
Former Head, Division of Cardiology, Sick Kids Hospital, Toronto

CHD facts

- CHD affects 1 in 100 newborns worldwide
- It is the most common birth defect
- More babies die of CHD than all childhood cancers combined



CHD facts

- ~257,000 Canadian CHD patients (60% are adults)
- Many patients will need multiple surgeries, interventions, and medications throughout their lives



CHD - Background

- Growing population, much larger than other well recognized disorders
- Complex medical and psychosocial needs throughout life
- **But...**
 - More adult CHD research and support is needed
 - Improved coordination in transition



CHD facts

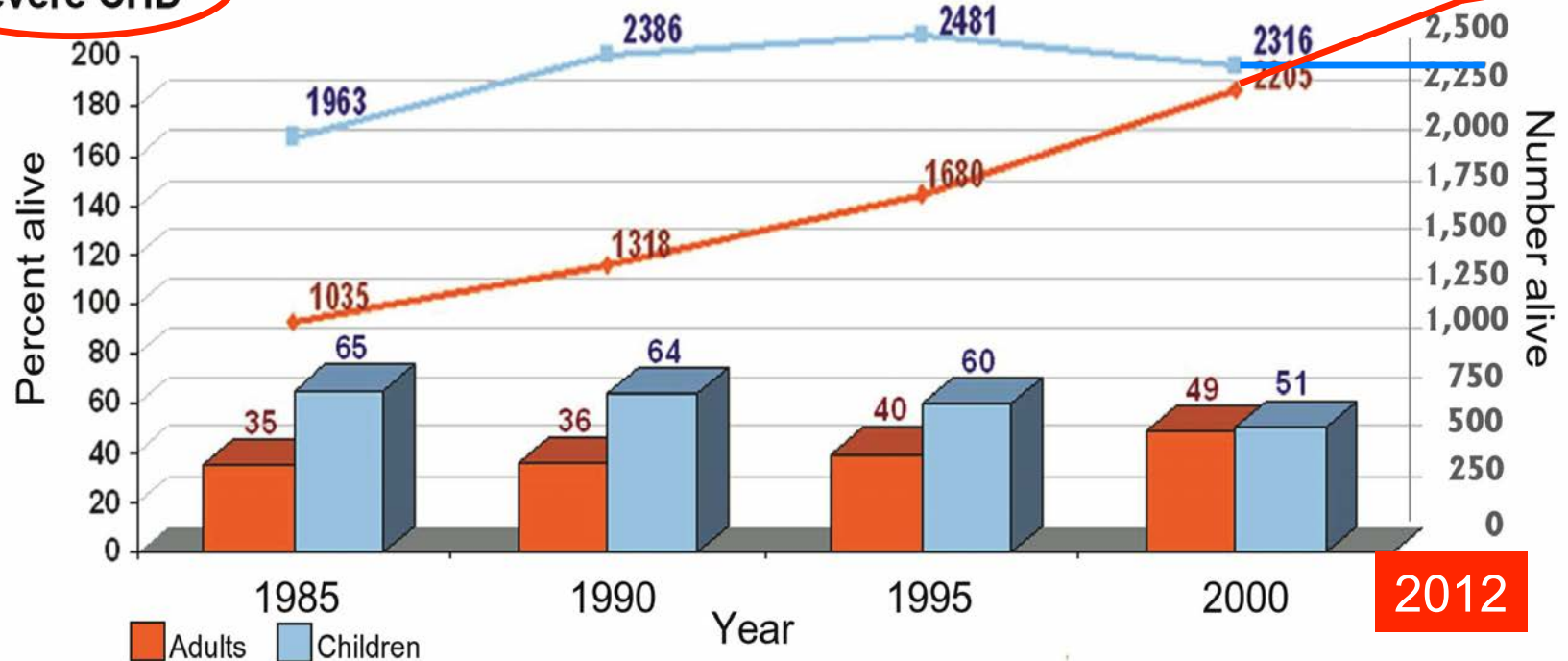
- In the 1960s the survival rate was ~20%
- In 2015 it is ~95%
- Now more and more patients with complex cases are surviving well beyond age 18



Changing age distribution of severe CHD: 1985-2000



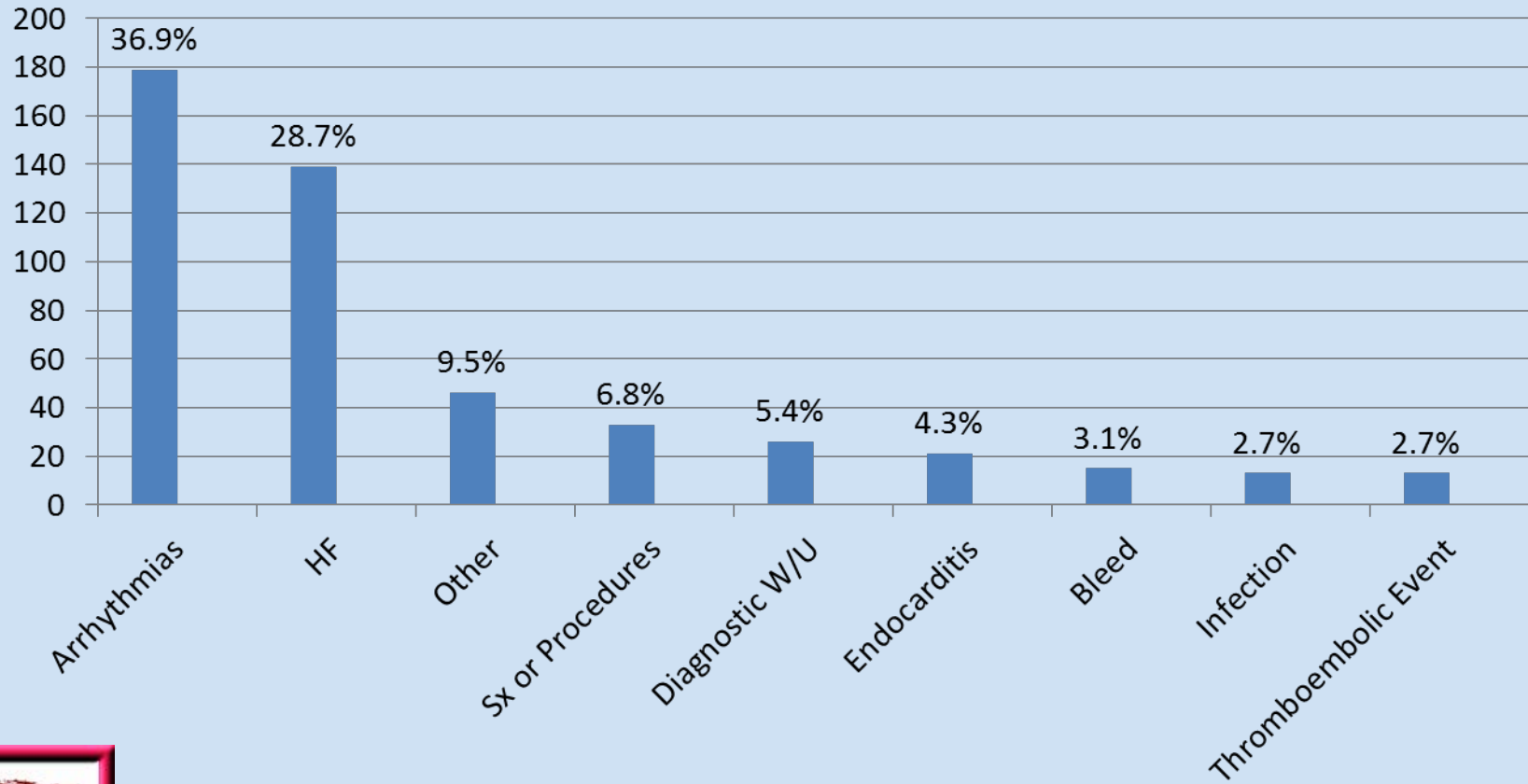
Severe CHD



Now about 180,000 Canadian adults with CHD



Reasons for admissions in Toronto

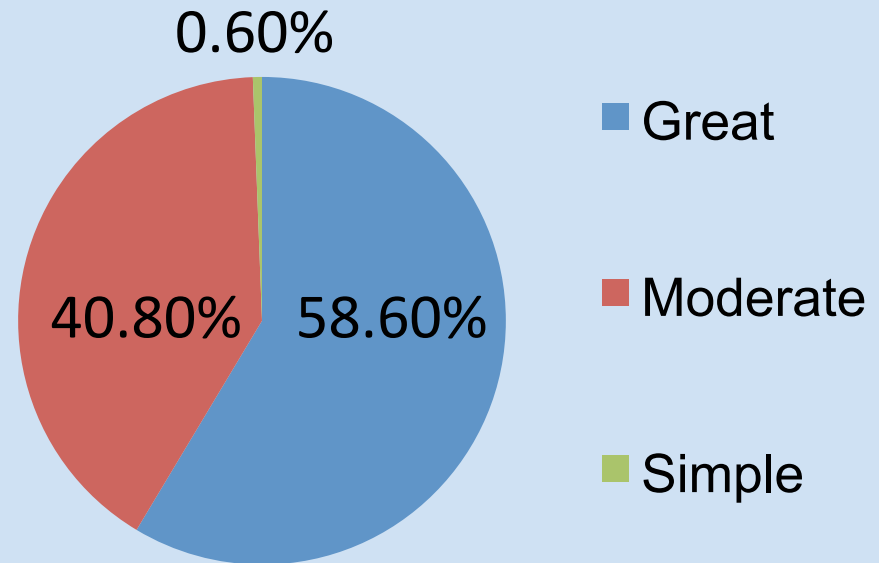


Courtesy by Qunyu Li, ACHD NP

Defect complexity

Between Jan. 2010-Dec 2012

Complexity	No
Great	284
Moderate	198
Simple	3
Total	485



Courtesy by Qunyu Li, ACHD NP

15 adult CHD (CACH) centres



CANADIAN ADULT
CONGENITAL HEART NETWORK
www.cachnet.org



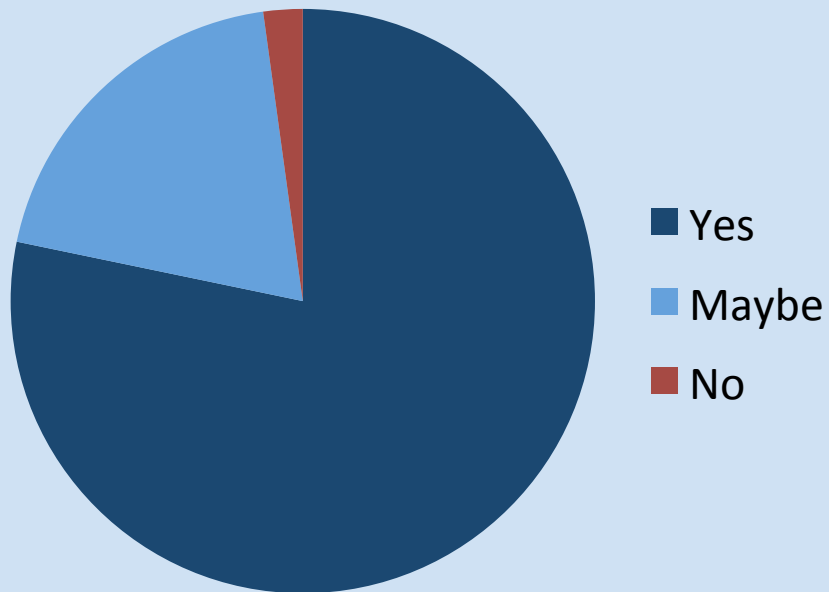
Main challenges

- CHD not well recognized in general population
 - obscured by acquired heart disease
- CHD not well represented by HSF – *Canada's heart organization*
- Difficulty finding adequate funding to meet objectives
- Apathy and lack of info among patients and public – CHD considered a childhood disorder that gets fixed

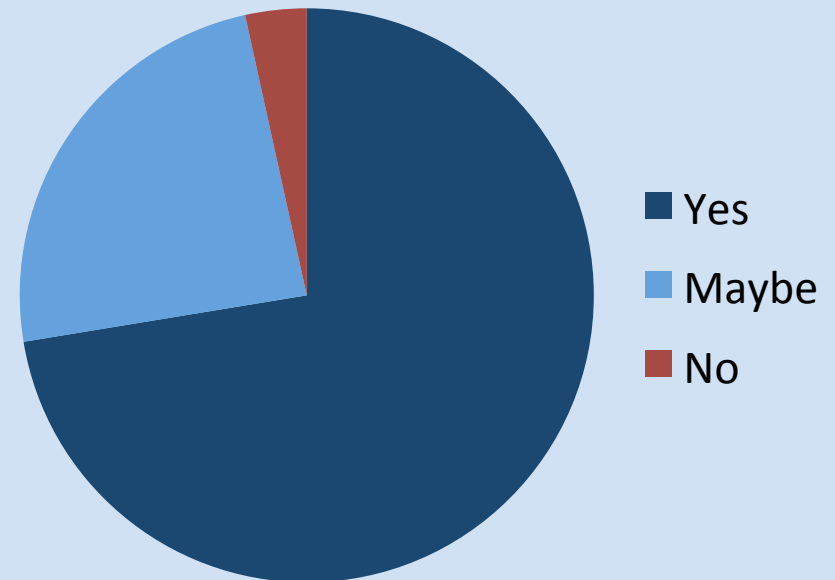
CCHA Patient Needs Survey: May-July 2014

Would you like to know more about CHD?

Patients

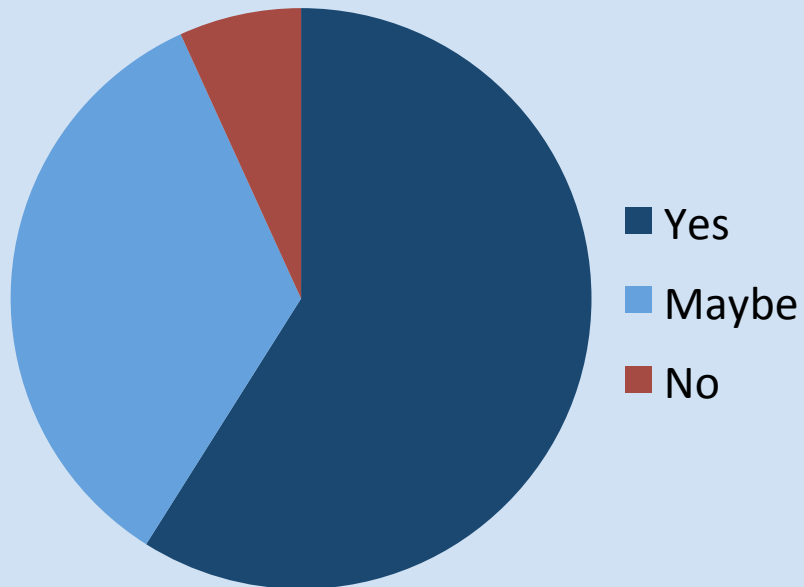


Parents of CHD child

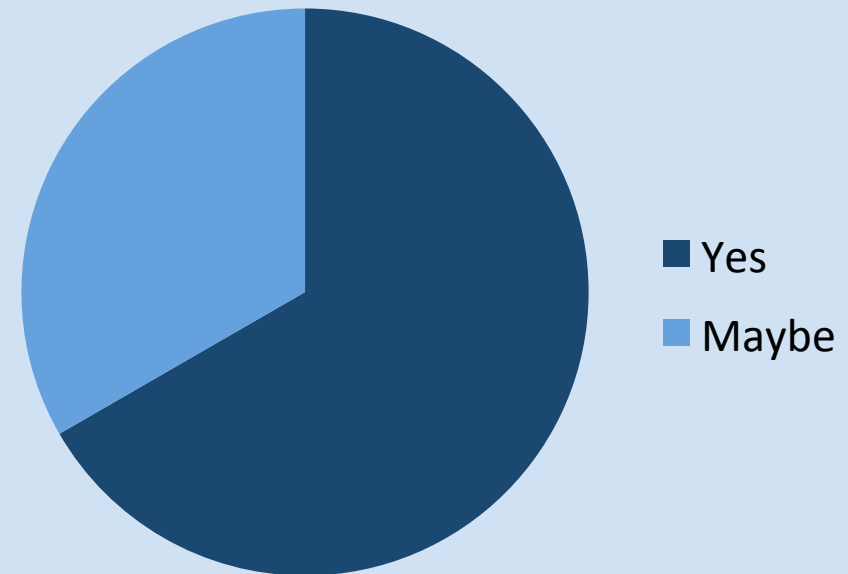


Would you be interested in attending a CHD info session?

Patients



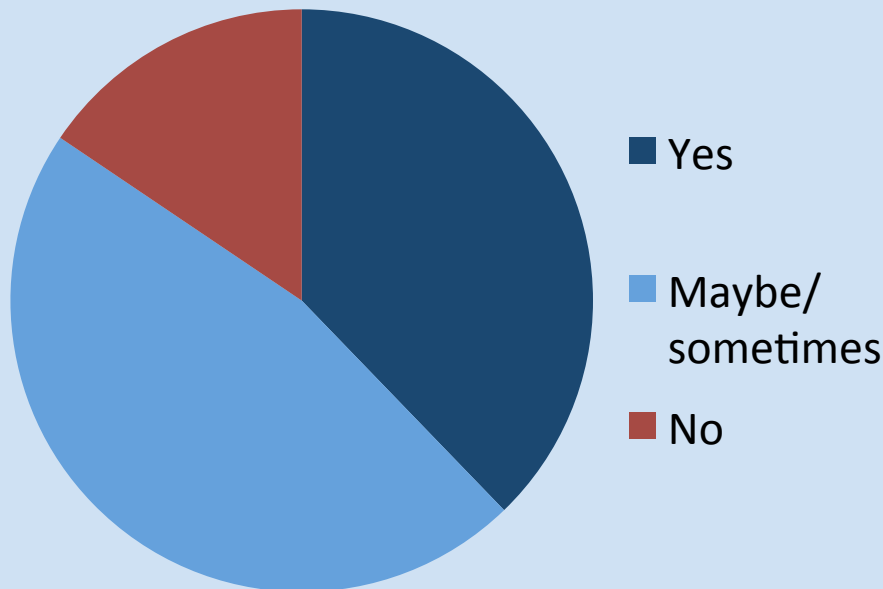
Parents of CHD child



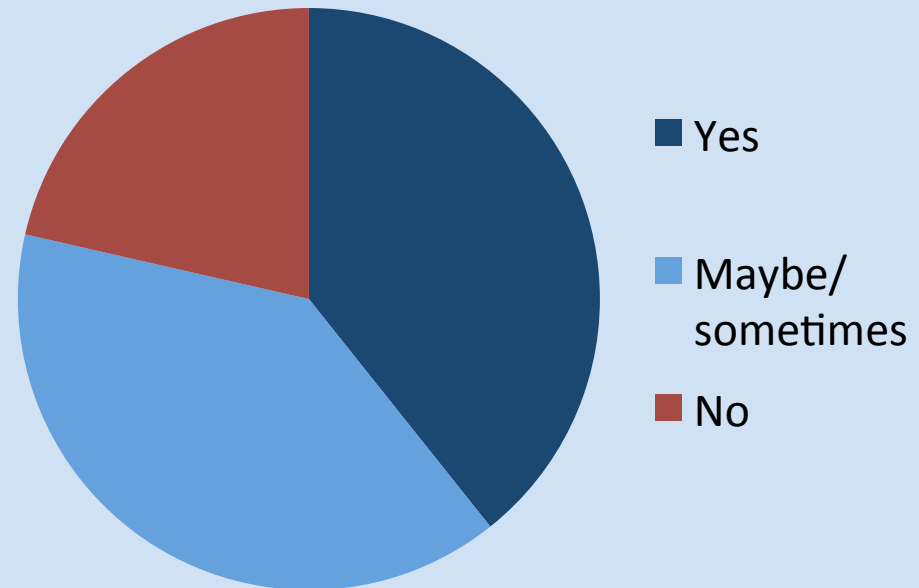
Do you struggle with issues related to your heart condition?



Patients



Parents of CHD child

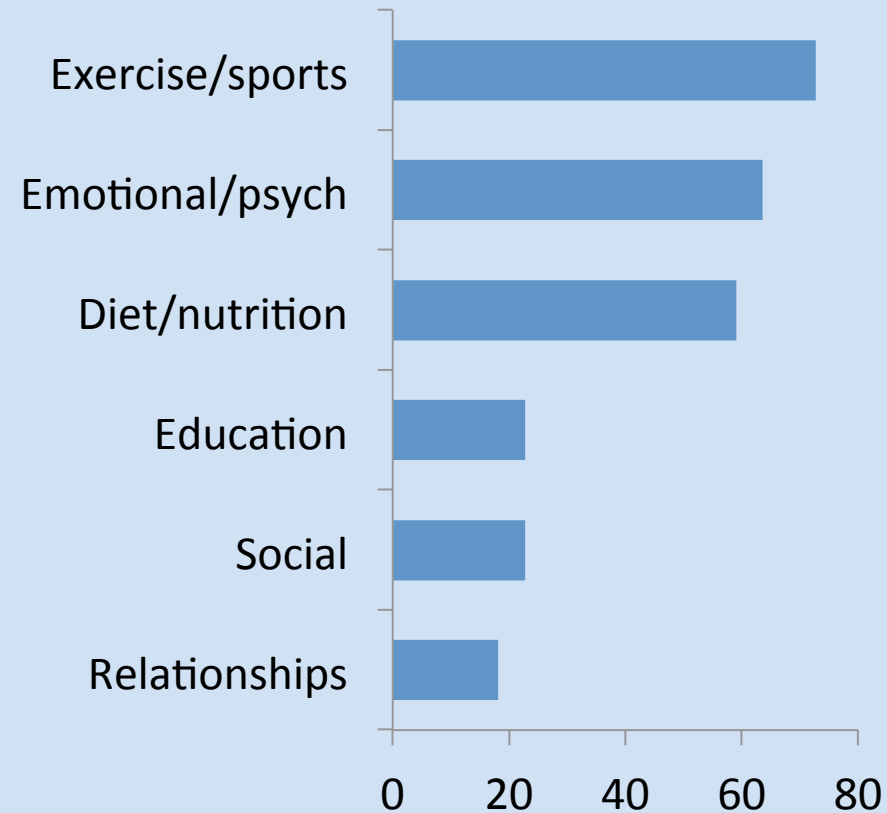


Please indicate the issues you/your child struggle with due to your heart condition

Adult CHD patients



CHD children



CHD patient support lacking

- No programs to address CHD-related anxiety and depression
- No exercise guidelines to address special needs of CHD patients
- No diet/nutrition education and support programs available
- Only 2 dedicated CHD psychologists in Canada
 - **Need cardiovascular community leaders to help CHD patients get the care they need and deserve**

**Canadian Congenital
Heart Alliance
(CCHA)**





Canadian Congenital Heart Alliance

Who are we?

- Launched in 2004
- Registered charity
- CHD patients, families, friends, and medical community
- Volunteer-run
- Run by a Board of Directors



Canadian Congenital Heart Alliance

- CCHA only organization in Canada attempting to address these needs
- ~75% of adult patients “lost to follow-up”¹
- Evidence that patients treated by adult CHD specialists have better outcomes²

1. “Lost to follow-up” means not known to be receiving cardiology follow-up care in specialized centres recommended by international guidelines
2. Mylotte D, et al. Specialized Adult Congenital Heart Disease Care: The Impact of Policy on Mortality. *Circulation* 2014;129:1804-1812.

Canadian Congenital Heart Alliance



Our mission

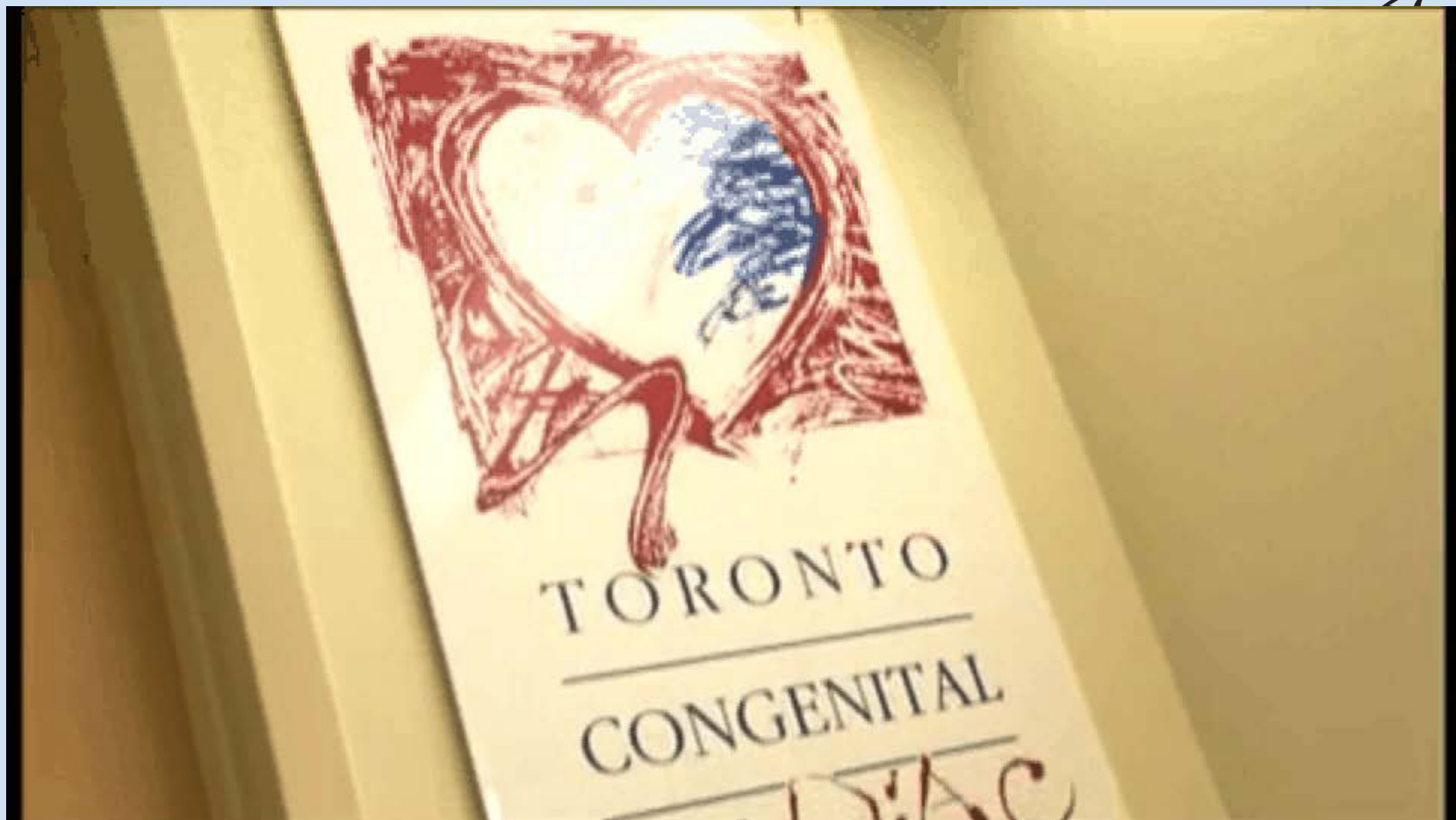
- To improve the quality of life and health for people with CHD by :
- Raising awareness
- Providing peer support, mentoring, and advocacy
- Advancing research



Our main message

- CHD is a lifelong disorder
- Patients can be repaired, but *not* fixed
- Patients and parents of CHD kids need to be proactive to get the expert care needed





Erwin Oechslin, MD, FRCPC, FESC
Director, Congenital Cardiac Centre for Adults, Toronto
General Hospital

CCHA activities

- Working with allied organizations for greater recognition and support
- Attend and speak at national and international CHD conferences
- Participate in patient education sessions
- Participate in fundraising walks and activities





Support Canada's #1 birth defect;
affecting 180,000 Canadians!

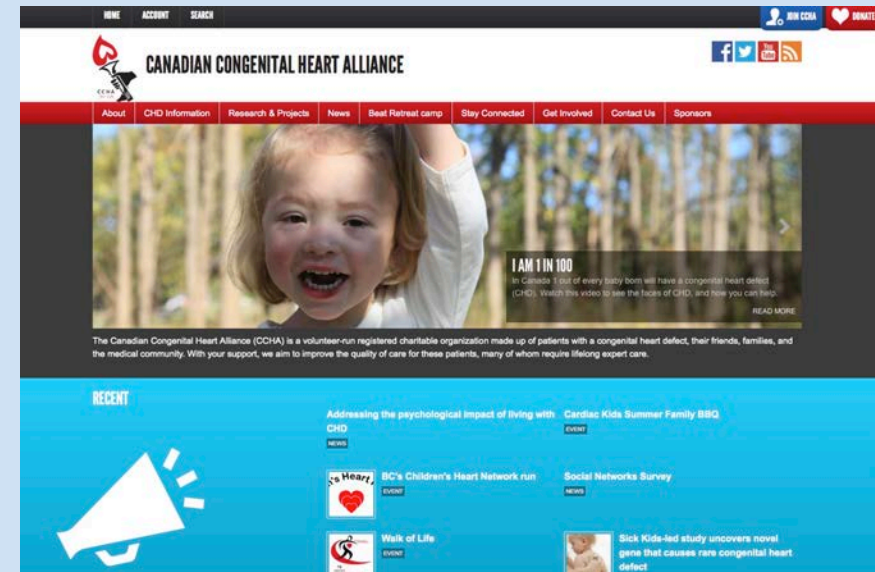
February 15, 2014

**CONGENITAL
HEART
WARRIORS
WALK 2014**



CCHA activities

- Educate patients and their families, cardiologists, and GPs about CHD
- Host an active CCHA website, Facebook page and Twitter
- Run Beat Retreat camp in Ontario
- Currently have CHD Awareness Day events in BC and ON



Chapter development

- Developing chapters across Canada to create unified voice for CHD patients
- Build support for healthcare groups – provide necessary funding where needed
- Provide local support and education for patients and parents





cchaforlife.org
info@cchaforlife.org
Twitter [@cchaforlife](https://twitter.com/cchaforlife)

Thank you!

