CANADIAN
CONGENITAL
HEART ALLIANCE

Importance of patient groups

CCHA – *for life!*

Canadian Congenital Heart Alliance (CCHA)

- Founded in 2004 in Toronto
- National voice of CHD community
- Kids and adults
- All volunteer
- Governed by elected Board

Our mission

Improve the quality of life and health outcomes for kids and adults with CHD by :

- Raising awareness of CHD
- Providing peer support, mentoring, influencing policy and procedures
- Promoting 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 lifelong expert care needed

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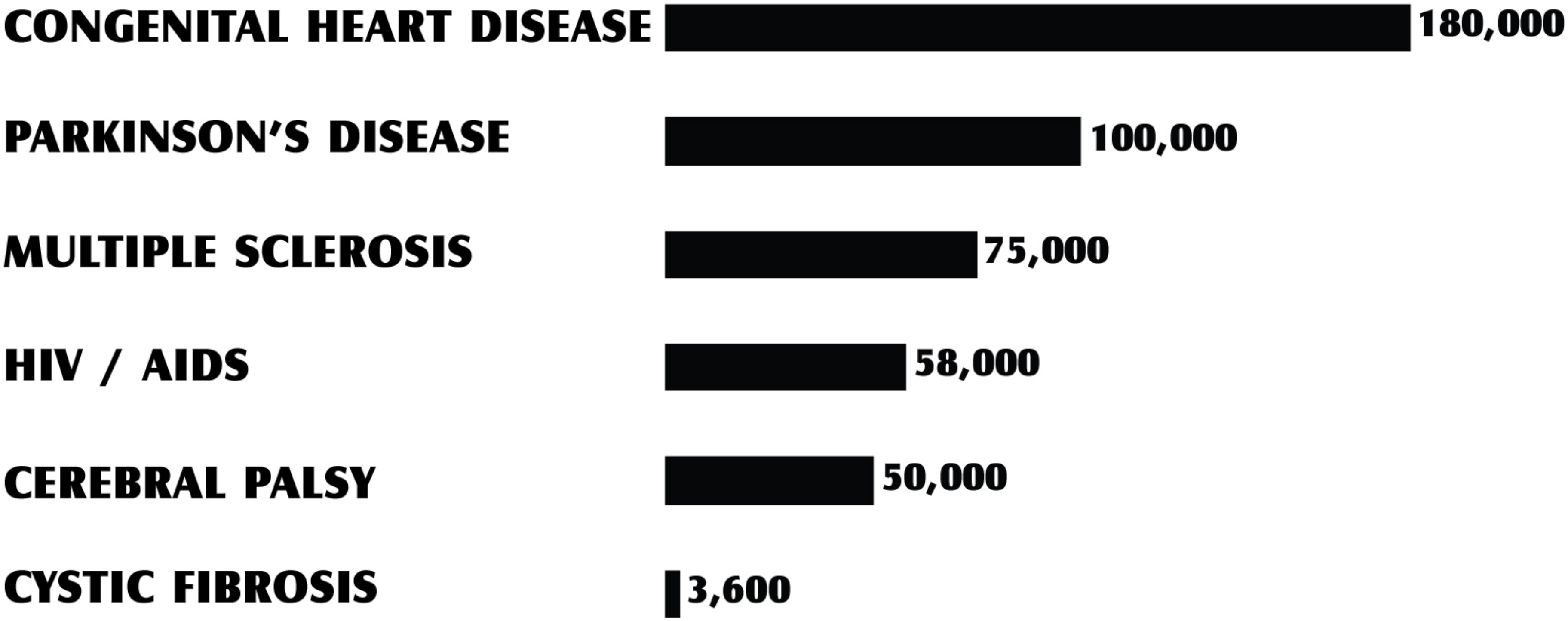
CANADIAN POPULATION DISEASE STATISTICS



*Sources: Epilepsy Ontario, Canadian Cystic Fibrosis Association, Public Health Agency of Canada (AIDS), Parkinson's Society of Canada, Canadian Congenital Heart Alliance, Multiple Sclerosis Society of Canada

Why there is a need

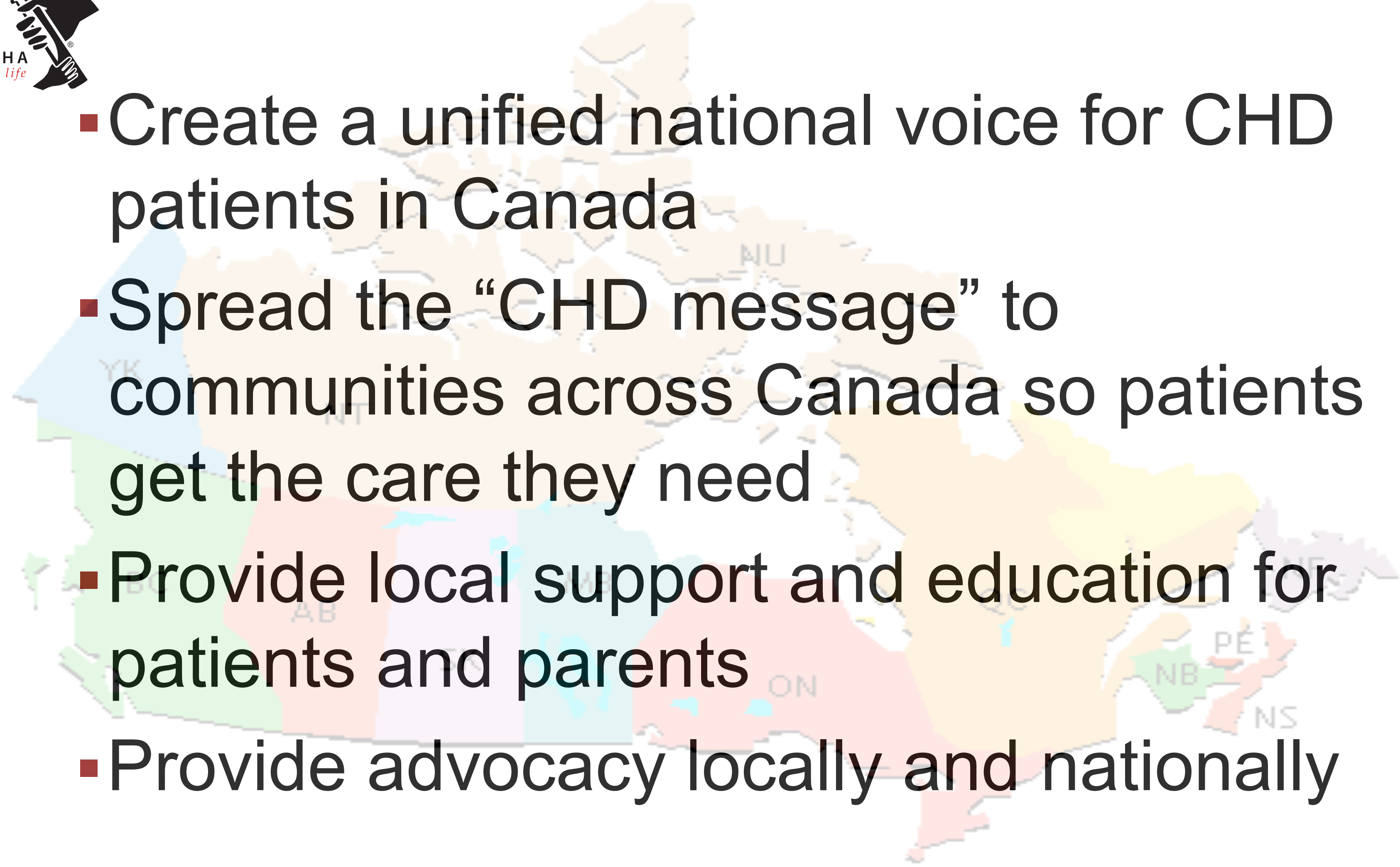
- CHD is the world's leading birth defect (~1 in 100)
- Historically, few made it past their teens. Now, ~95% make it to adulthood
- ~180,000 Canadian CHD patients (more than 100,000 are adults)

But…

Only ~ 23% of ACHD patients followed by an ACHD specialist

- "Feel fine" until they end up in ER or worse
- Don't know that adult CHD specialists are available
- Can't afford to travel to major centre
  - **CRISIS in ACHD care**

CCHA chapter development



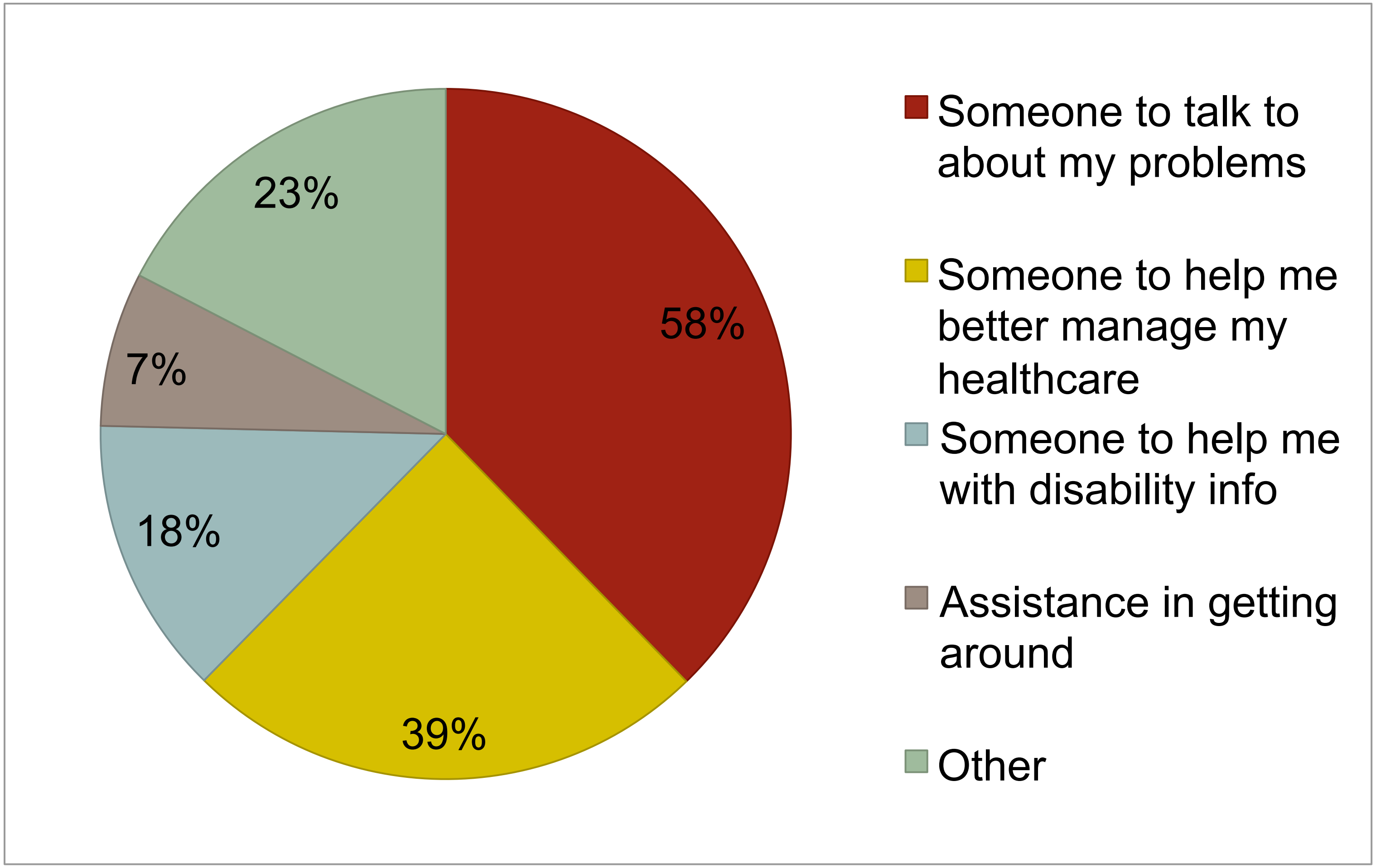
- Create a unified national voice for CHD patients in Canada
- Spread the “CHD message” to communities across Canada so patients get the care they need
- Provide local support and education for patients and parents
- Provide advocacy locally and nationally

What do patients want?

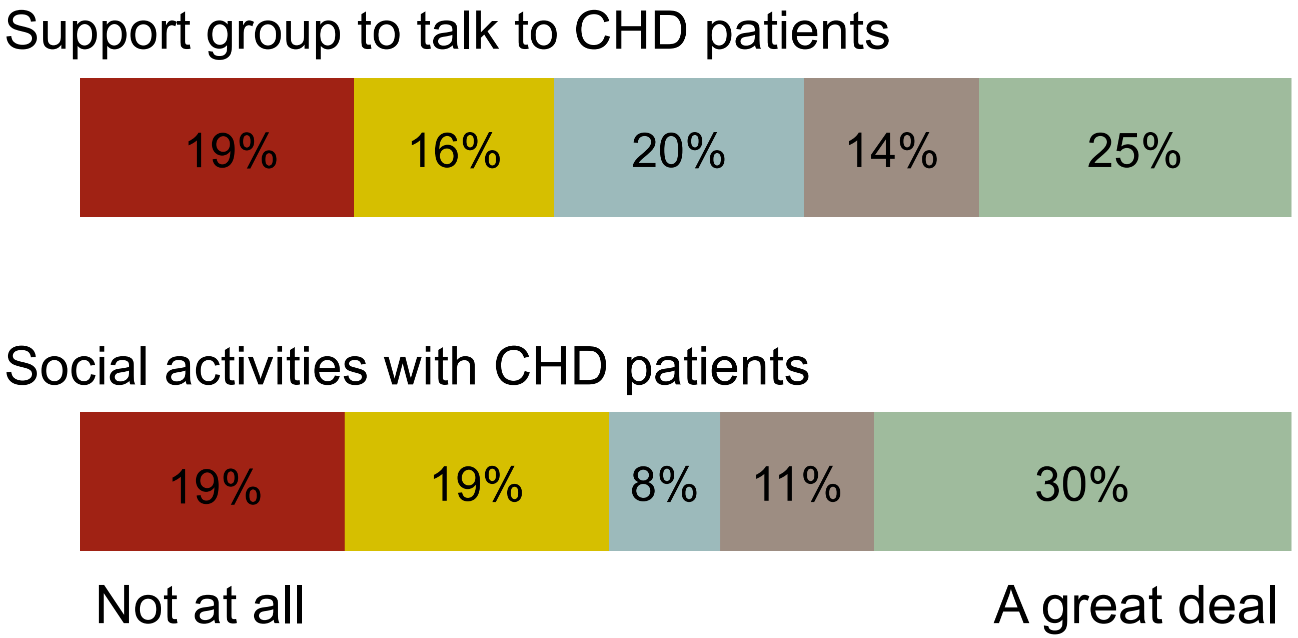
- Two surveys
- Emailed to CCHA members
- Posted on CCHA website and Facebook page

➢ 122 responses from adults with CHD

If you would like support, what type would you like?



Indicate how much you think you'd benefit from the following



Survey: other findings

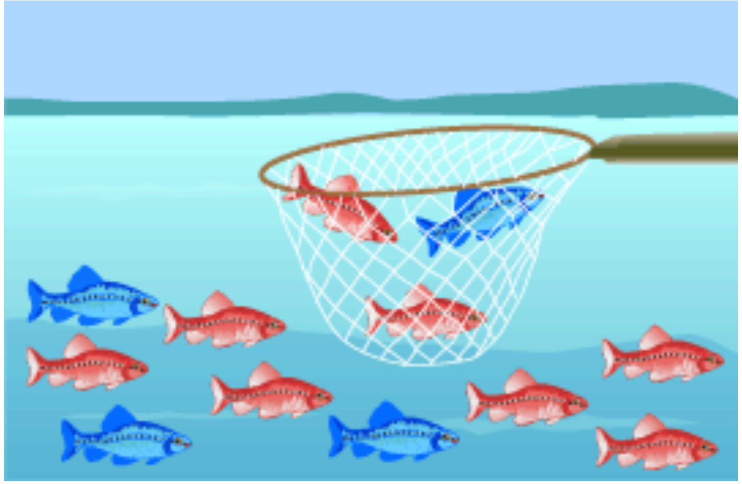
- 89% are satisfied or very satisfied with their medical care
- Most want a support group and social activities
- Lack of emotional/psychological support
- Concerns re: pregnancy and childbirth
- Consult with nutritionist re. weight loss
- Insurance hard to get or too expensive

Common challenges

- Self-esteem
- Fear, anxiety, depression
- Exercising safely
- Keeping up with work/schoolwork
- Keeping up with diet and diet restrictions
- Less energy to keep up with friends
- Trying to change from sedentary lifestyle

Important limits of survey

- 100,000 adults in Canada with CHD
- ~350 are members of CCHA
- Only 118 adult patient participated in survey
    - Survey is snapshot



Providing patient support

- Don’t call it a “support group”
- Approach it like driving with your teenager

(provide support while doing something else)

- “Package it” in fun activities
- Encourage people to participate

- ➢CCHA’s Beat Retreat camp

CCHA’s Beat Retreat

- Adult weekend for CHD patients in Ontario
- 23 “campers” in 2012
- Extended to 4 days due to demand
- Cost subsidized by CCHA (camper pays $25)
- Medical professionals attend as volunteers/ information resource

Beat Retreat objectives

- Create support network of patients
- Learn from others/share experiences
- Develop confidence/knowledge to manage healthcare
- Promote healthy/active lifestyle
- Foster self-esteem

CCHA's Beat Retreat

- True camp experience – rustic but comfortable
- Camp activities: campfires, canoeing, crafts, archery, initiatives course, yoga, badminton, hiking, polar bear dip
- Informal/formal educational component

Camper’s comments

“The opportunity to ask questions and just chat about life experiences with others who have shared similar experiences is invaluable.”

“Never a dull moment – there was always something to do… low ropes, initiatives, rock climbing, yoga, canoeing, arts & crafts or hiking.”

Camper's comments

"My favorite part of this year's camp was all of us sitting around a campfire, roasting gooey marshmallows for our s'mores, and listening to the stories, issues, and concerns we all share."

"I found it was a great opportunity to meet, interact and share stories with others, who like myself, have lived with cardiac challenges, setbacks and triumphs all of their lives. It was a great experience."

Camper’s comments

“The campfires were a blast. It’s always a great experience to connect with other people who have CHD and see what they have achieved in life.”

“In any setting, I’m always amazed to be around people who have had similar medical experiences, and persevered. Camping with them brings our collective strength to a whole new level!”

Beat Retreat outcomes

- Growing steadily; high return rate
- Participants build/maintain relationships (Facebook, organize other activities)
- Patients "thirsty" for more information
- Must be followed in clinic to attend
- ***Healthcare participants/observers learn too***

the beat retreat

….since 2009

Summary

- CCHA only national patient organization supporting kids and adults with CHD
- Crisis in ACHD – need more funding, education, awareness, and support so patients can live long, healthy lives
- Need improved transition programs so patients don’t get “lost to follow-up”

Conclusions

- Peer to peer support can be beneficial for those who want it (some may just want it from time to time)
- Provide fun activities in a supportive setting to engage patients
- Facilitators can provide useful information and also learn

CCHA in the community

ACHD Symposium

Walk of Life

CCHA Social Night

Sick Kids Education Family Day

CCS Congress

Lions Club spring fling

Visit us at

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Thank you!