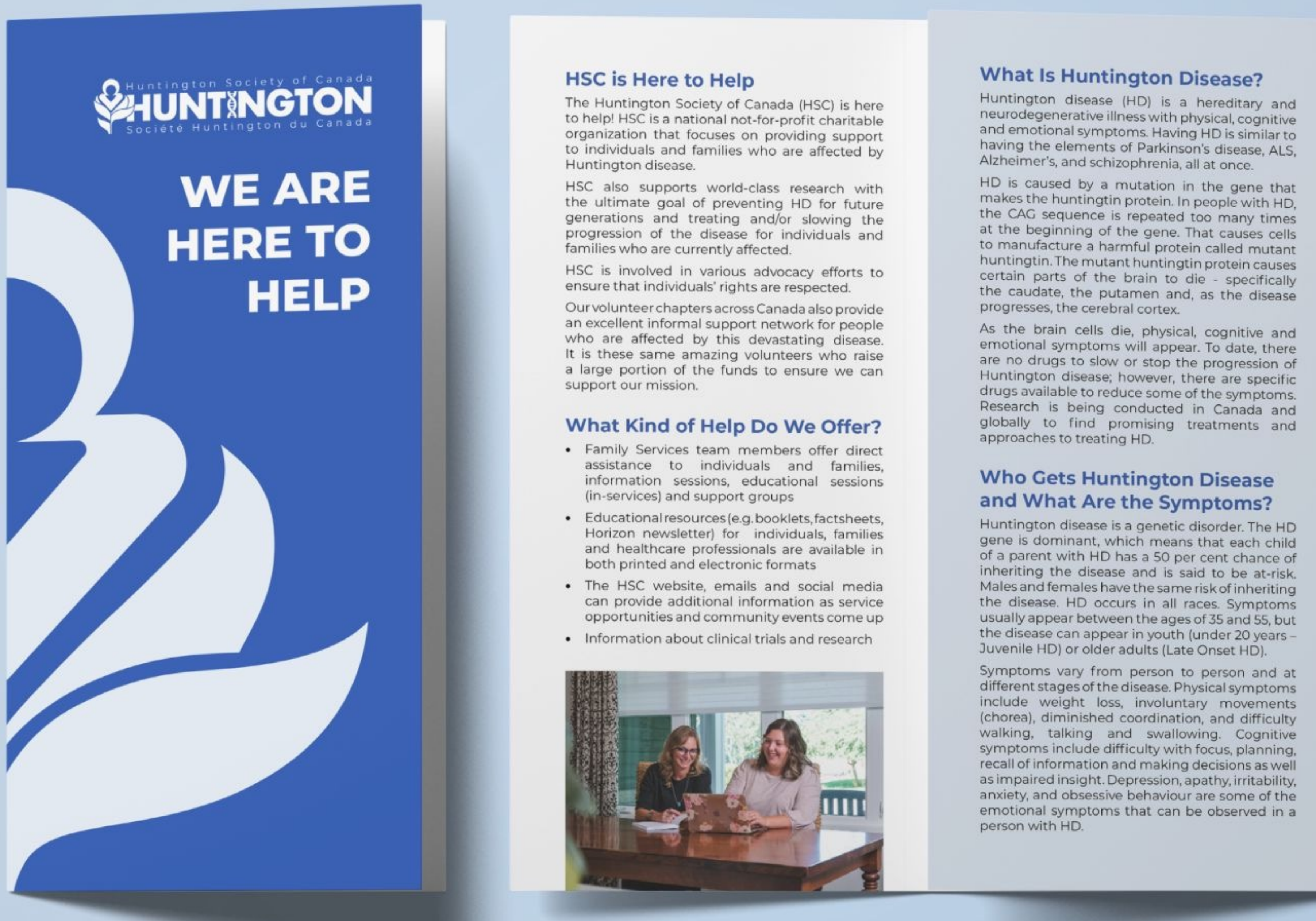
Centres for HD CARE
(Clinical And Research Excellence)

A Model for Equity and Standardization of Care across Canada

Shelly Redman, CEO
Huntington Society of Canada



Huntington Society of Canada
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WE ARE HERE TO HELP

HSC is Here to Help

The Huntington Society of Canada (HSC) is here to help! HSC is a national not-for-profit charitable organization that focuses on providing support to individuals and families who are affected by Huntington disease.

HSC also supports world-class research with the ultimate goal of preventing HD for future generations and treating and/or slowing the progression of the disease for individuals and families who are currently affected.

HSC is involved in various advocacy efforts to ensure that individuals' rights are respected.

Our volunteer chapters across Canada also provide an excellent informal support network for people who are affected by this devastating disease. It is these same amazing volunteers who raise a large portion of the funds to ensure we can support our mission.

What Kind of Help Do We Offer?

- Family Services team members offer direct assistance to individuals and families, information sessions, educational sessions (in-services) and support groups
- Educational resources (e.g. booklets, factsheets, Horizon newsletter) for individuals, families and healthcare professionals are available in both printed and electronic formats
- The HSC website, emails and social media can provide additional information as service opportunities and community events come up
- Information about clinical trials and research

What Is Huntington Disease?

Huntington disease (HD) is a hereditary and neurodegenerative illness with physical, cognitive and emotional symptoms. Having HD is similar to having the elements of Parkinson's disease, ALS, Alzheimer's, and schizophrenia, all at once.

HD is caused by a mutation in the gene that makes the huntingtin protein. In people with HD, the CAG sequence is repeated too many times at the beginning of the gene. That causes cells to manufacture a harmful protein called mutant huntingtin. The mutant huntingtin protein causes certain parts of the brain to die - specifically the caudate, the putamen and, as the disease progresses, the cerebral cortex.

As the brain cells die, physical, cognitive and emotional symptoms will appear. To date, there are no drugs to slow or stop the progression of Huntington disease; however, there are specific drugs available to reduce some of the symptoms. Research is being conducted in Canada and globally to find promising treatments and approaches to treating HD.

Who Gets Huntington Disease and What Are the Symptoms?

Huntington disease is a genetic disorder. The HD gene is dominant, which means that each child of a parent with HD has a 50 per cent chance of inheriting the disease and is said to be at-risk. Males and females have the same risk of inheriting the disease. HD occurs in all races. Symptoms usually appear between the ages of 35 and 55, but the disease can appear in youth (under 20 years – Juvenile HD) or older adults (Late Onset HD).

Symptoms vary from person to person and at different stages of the disease. Physical symptoms include weight loss, involuntary movements (chorea), diminished coordination, and difficulty walking, talking and swallowing. Cognitive symptoms include difficulty with focus, planning, recall of information and making decisions as well as impaired insight. Depression, apathy, irritability, anxiety, and obsessive behaviour are some of the emotional symptoms that can be observed in a person with HD.

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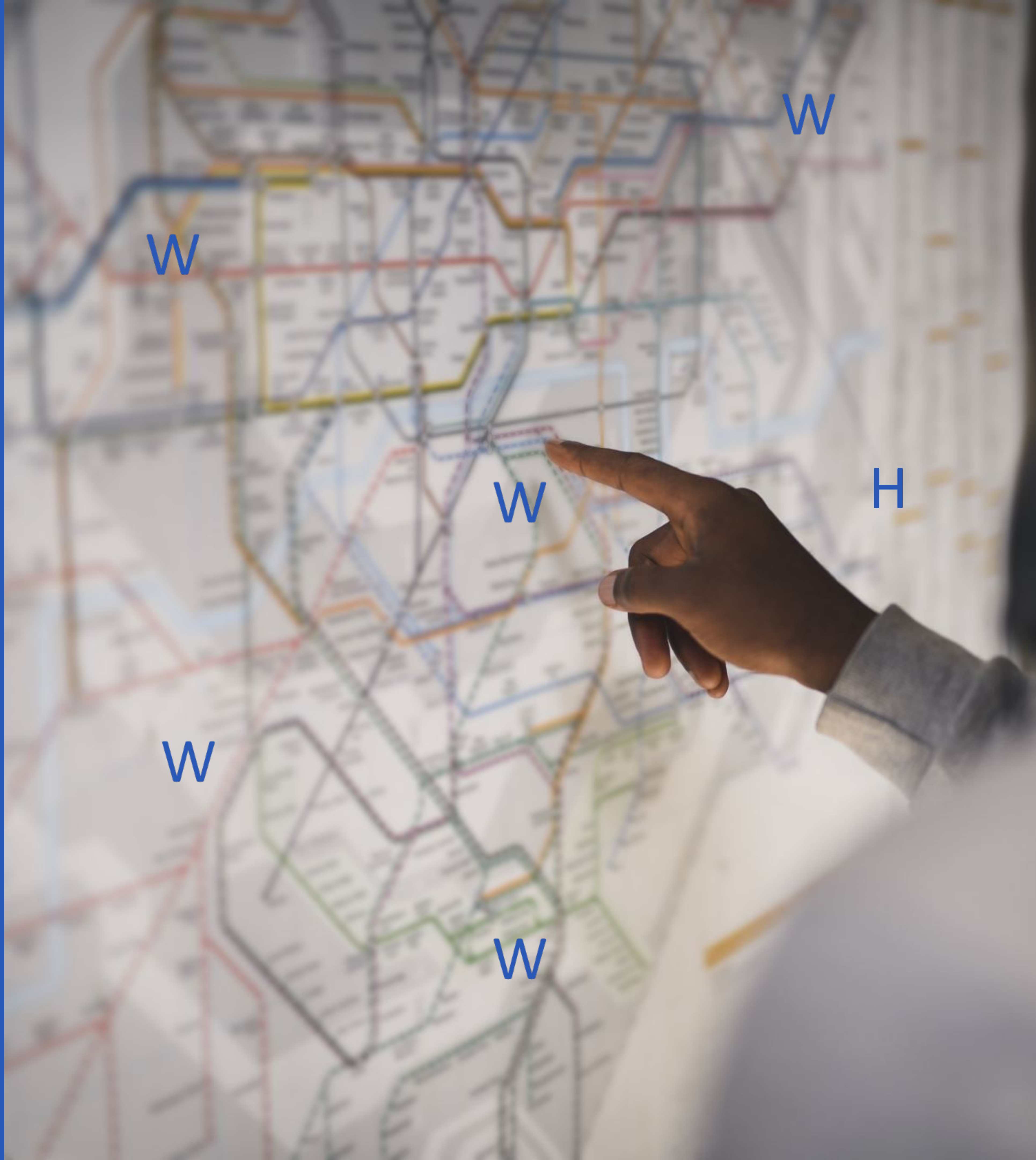
Presentation Outline

Let’s take a journey through the **5Ws + H** to get to know our Family Services Team and the Centres for HD CARE model!



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CAGT REPEATS OF
40 OR MORE
EVENTUALLY LEAD TO
HUNTINGTON DISEASE

50% EACH CHILD OF A PARENT WITH HD, **EITHER MALE OR FEMALE**, HAS A 50% CHANCE OF INHERITING THE GENE

1 IN EVERY 7,000
CANADIANS HAS HD

1 IN EVERY 5,500
CANADIANS IS AT-RISK FOR HD

ADULT-ONSET HD IS THE MOST COMMON PRESENTATION OF HD, WITH SIGNS AND SYMPTOMS USUALLY APPEARING BETWEEN
AGES 35 TO 55

~10% OF HD CASES ARE LATE-ONSET HD, DIAGNOSED AFTER AGE 60 AND USUALLY PROGRESSING MORE SLOWLY

~10% OF HD CASES ARE JUVENILE HD, DIAGNOSED BEFORE AGE 20 AND USUALLY PROGRESSING FASTER

CURRENTLY, THERE IS NO KNOWN CURE FOR HUNTINGTON DISEASE (HD)

Shelly Redman

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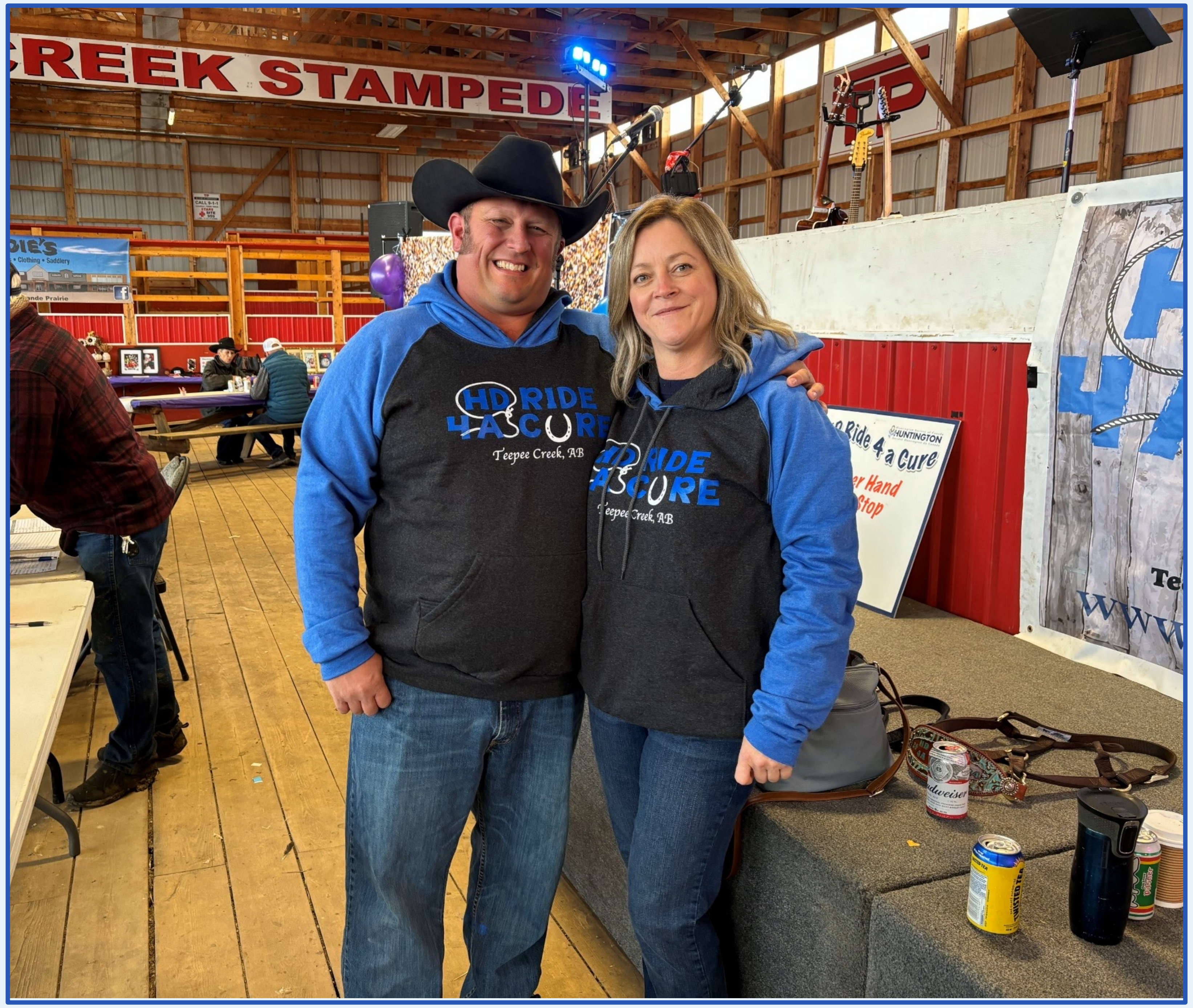
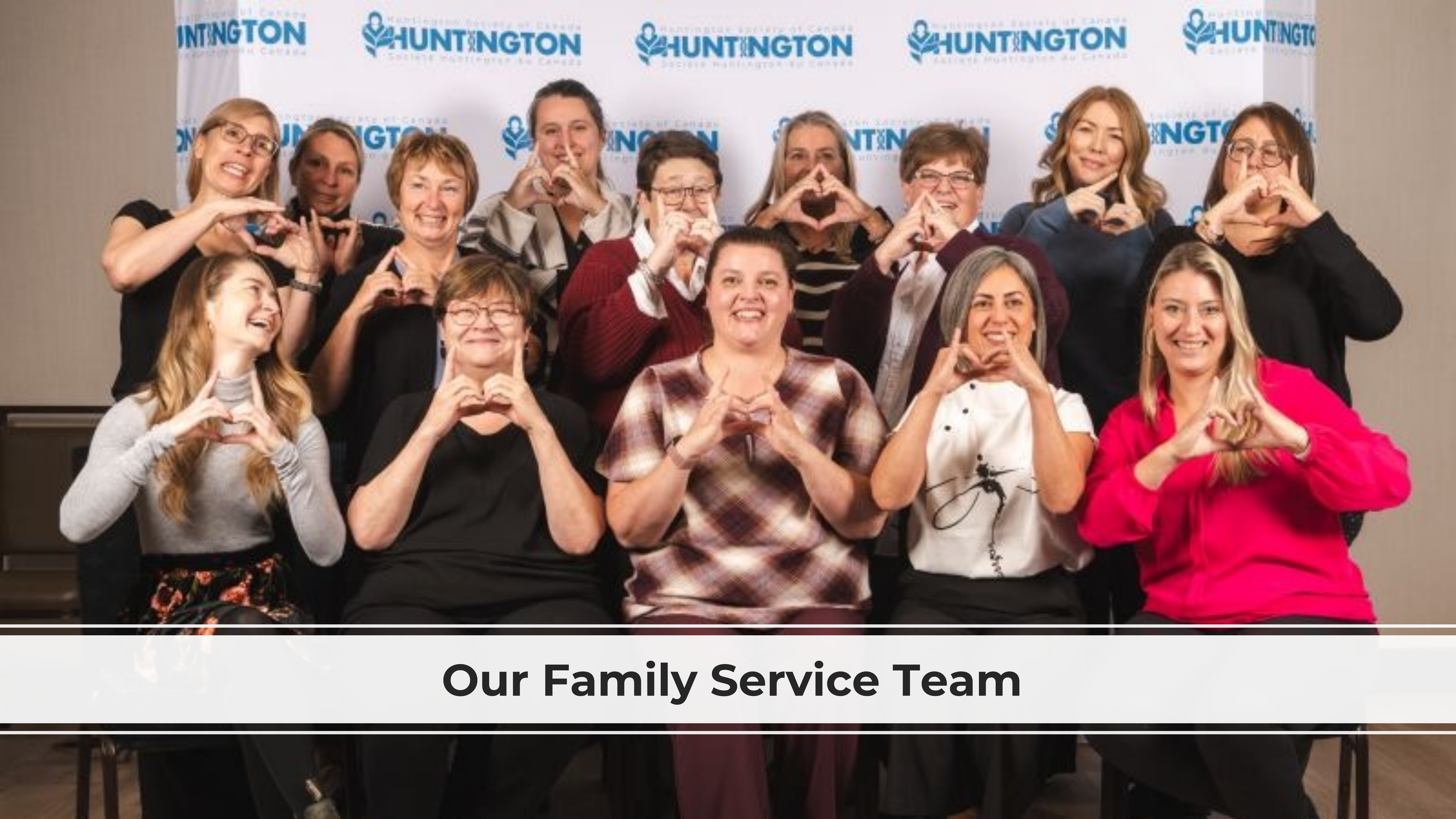


Our Family Service Team



Statistics for Fiscal 2024-25

Direct Support	Mutual Support
Number of open files = 2,753	Number of Support Groups = 22 (increase of 3)
Phone Calls = 5,052 (39% increase)	In-Person Support Group Events = 940 (31% increase)
Emails = 12,258 (14% increase)	Virtual Support Group Events = 3,628 (61% increase)
Home visits = 661 (27% increase)	Number of clients involved in groups = 335
Virtual appointments = 754 (27% increase)	

Statistics for Fiscal 2024-25

Information & Education	Partnerships
Online Referrals = 395 (1,261% increase)	In-Person Genetic appointments = 13 (increase from 0)
In-person Case Consultations/Education sessions/LTC in-services = 163 (120% increase)	Virtual Genetic appointments = 30 (58% increase)
Virtual In-Person Case Consultations/Education Sessions/LTC In-Services = 180 (5% decrease)	In-Person HD Clinic appointments = 432 (25% decrease)
	Virtual HD Clinic events = 188 (36% increase)
	New Referrals to Genetic/HD/MD clinics = 25 (62% decrease)

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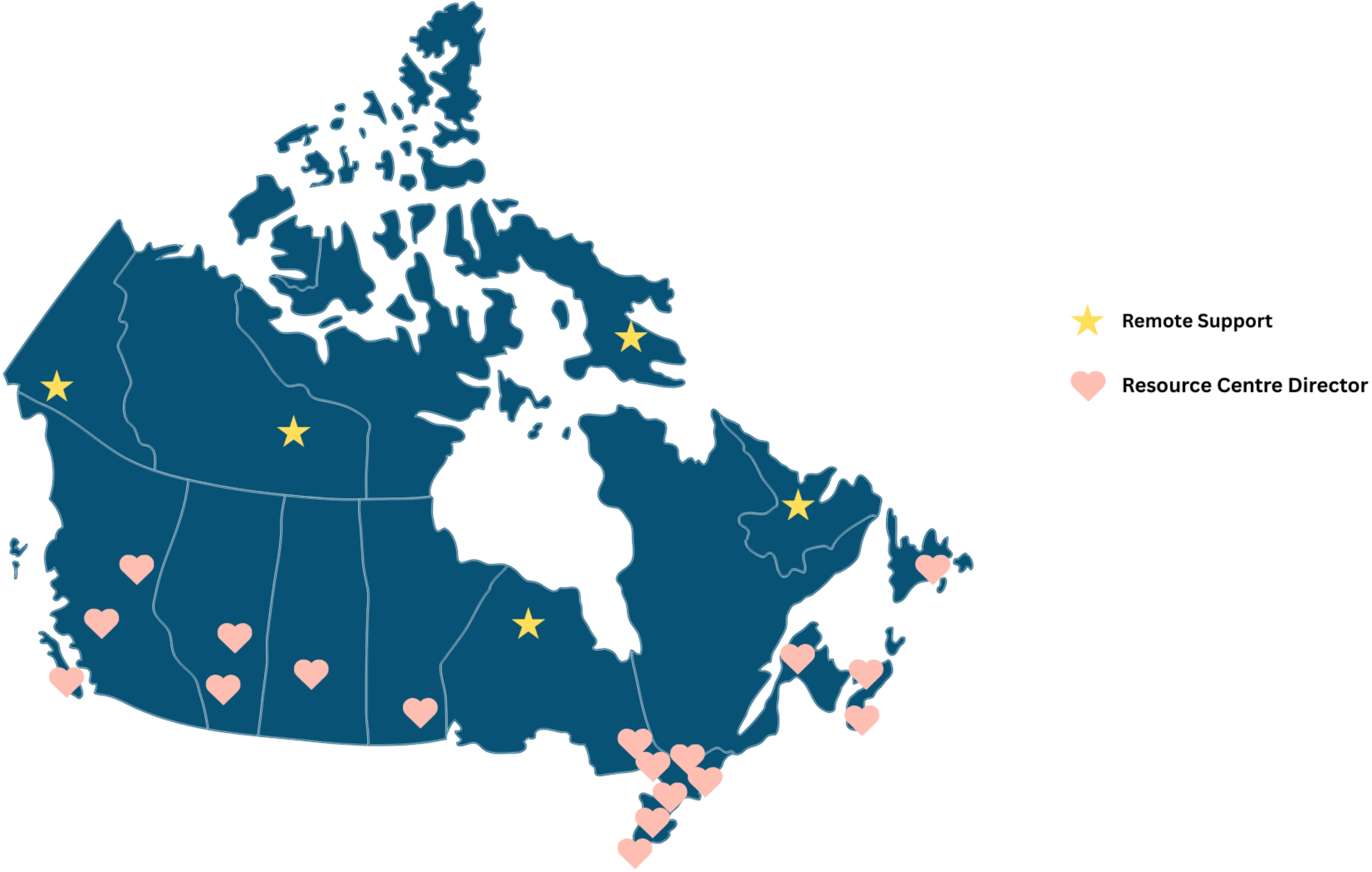
★ Remote Support
♥ Resource Centre Director

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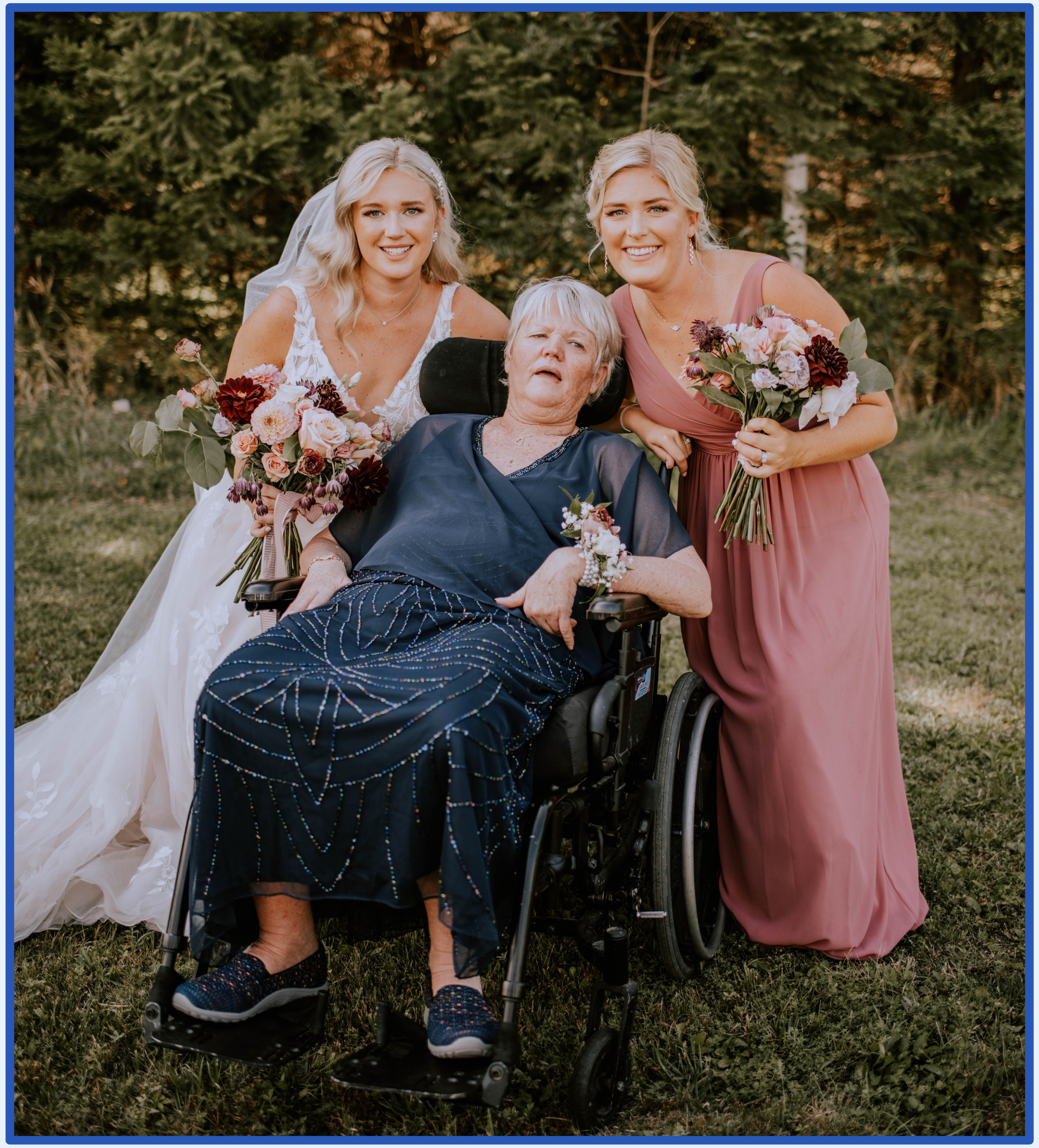
Centres for HD CARE

- The aim of the Centres for HR CARE (Clinical And Research Excellence) model is to provide equity in service provision across all sites
- This is achieved by providing funding to support a full compliment of multidisciplinary team members in each site
- This is amplified by matching these clinics with specific underserviced regions to ensure all Canadians have reasonable access to clinic services



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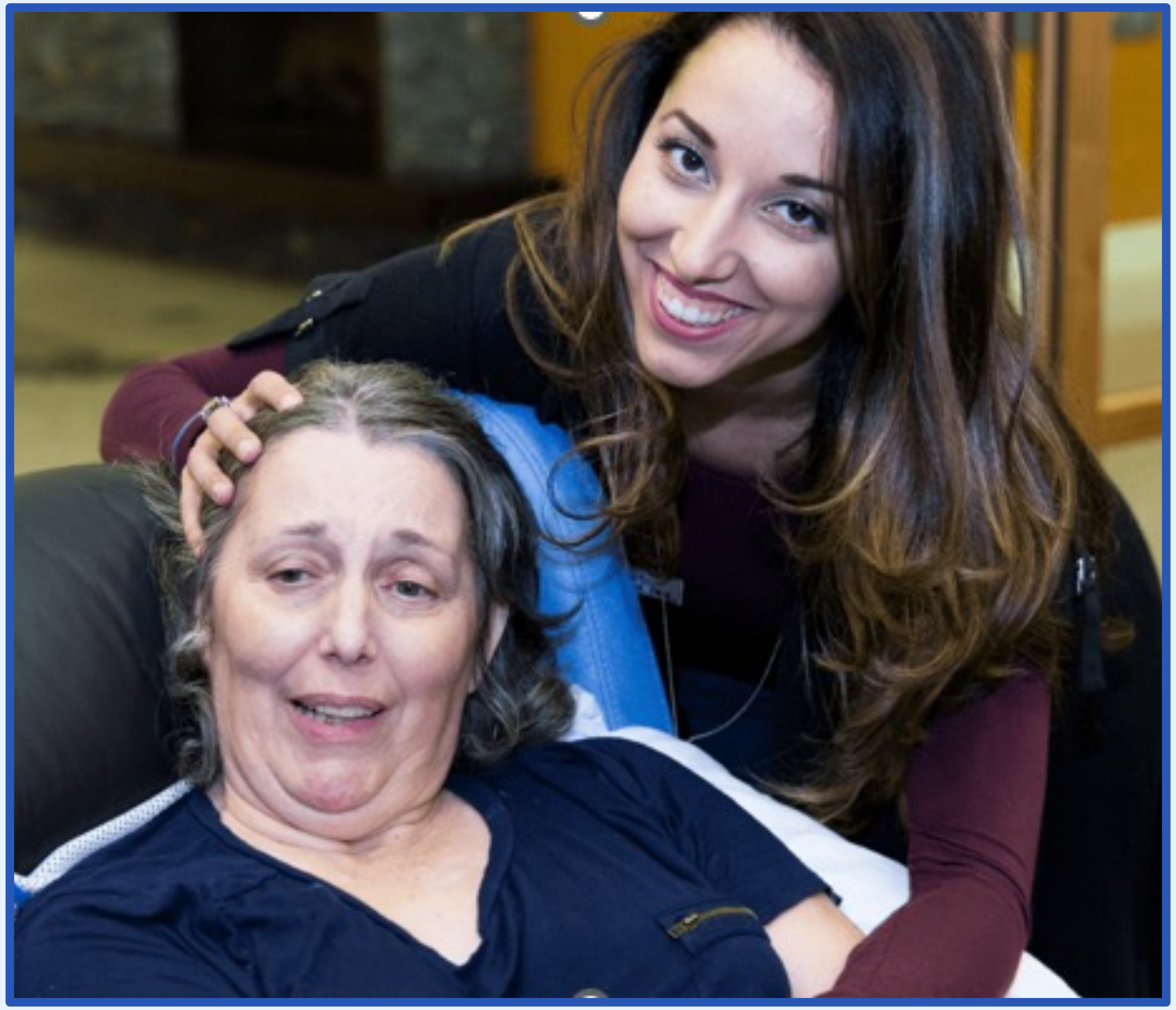
HDSA Centre of Excellence (COE) Model

- HDSA's COE program started in 1997 with their very first site
- They now support 56 centres and 11 partner sites to a total of $2 million in funding per year
- Each site is responsible to provide outreach to underserviced areas, either through outreach visits or virtual support to neurologists, psychiatrists, LTC homes, etc. to manage the patients that they have
- Offers 3 different tiers of patient populations
  - Level 1 (25-50 patients) = up to $20k
  - Level 2 (50-100 patients) = up to $50k
  - Level 3 (150+ patients) = up to $75k



How Do We Get There?

- Phase 1 involves pan Canadian community assessment and gap analysis
  - Required to identify underserviced regions and population groups
  - Test hypotheses and identify new issues
  - Involve a diverse stakeholder group
- Phase 2 involves model development including clinic manuals, contracts, clinic evaluation and data management tools, RFP process

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WHY HUNTINGTON

Because our HD community is at the heart of all that we do!

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