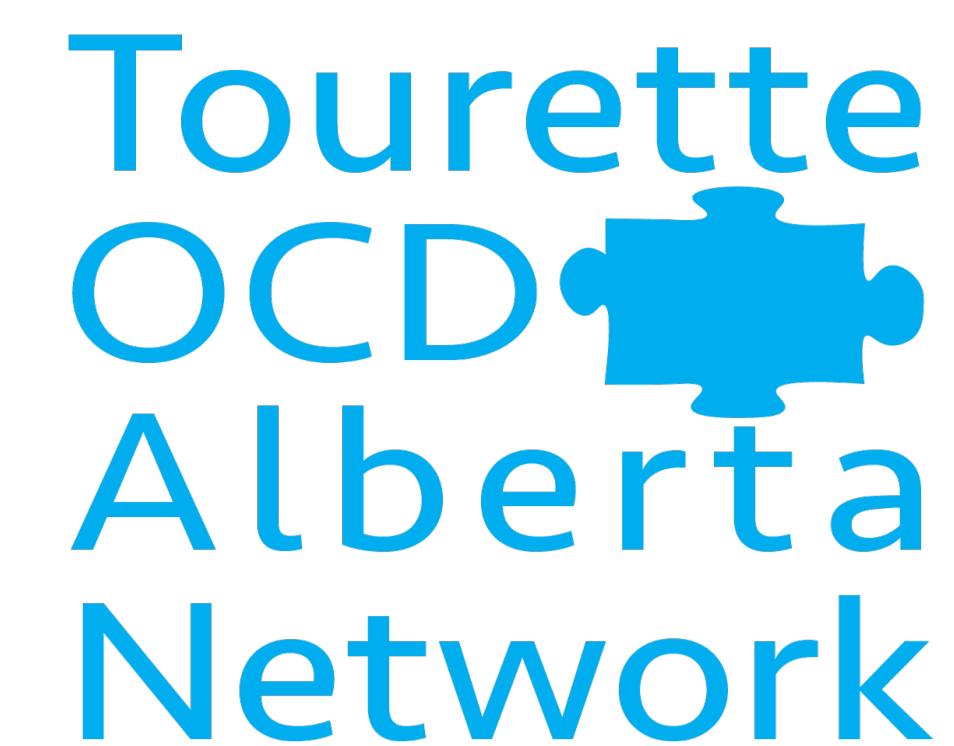


# The Tourette OCD Alberta Network: Development of an Online Parental Peer Discussion Group

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## Background

- Peer support is a pathway to increased knowledge and well-being through empathetic discussion.
- Peer support for parents affected by Tourette syndrome is acutely limited in a province as geographically vast as Alberta, Canada.
- Previous research foregrounded the desire and need for parents to share their lived experience with other parents.

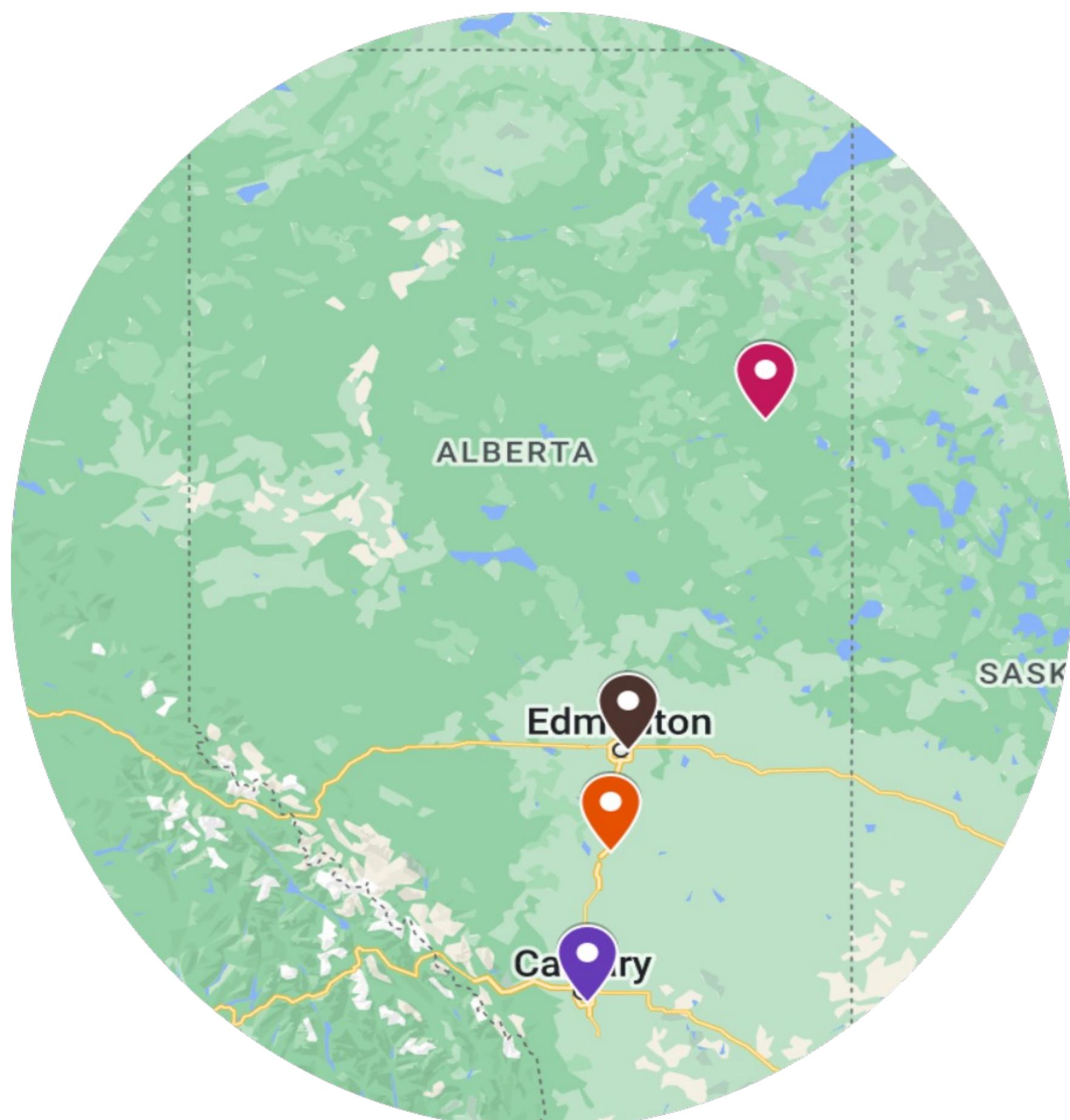
## Method

- In 2021, families were invited throughout Alberta to participate in virtual psychologist peer support groups for parents of children with TS.
- 26 families participated in two groups: 15 in the first group and 11 in the second.
- Parents and families proposed topics and issues for discussion.
- A discussion agenda was devised, covering a range of TS topics, comorbidities, and associated issues.
- Two peer support groups took place in blocks of 5 weeks, meeting online in the evening for 1.5 hours discussion once a week.

## Weekly Discussion Agenda

Week	Topic
1	Relationship challenges and family dynamics
2	Emotion regulation, anxiety, rigidity, & perfectionism
3	Coping – for parents and for the children
4	Building confidence and self-efficacy to combat stigma associated with tics
5	ADHD, frustration, boredom tolerance, managing schoolwork and behavioral expectations

- Alberta, Canada is 660,000 sq kilometers. The discussion group took place between families in four main cities of Alberta: Calgary, Edmonton, Red Deer and Fort MacMurray.



## Results

### 1 Parental input in proposing topics

- Parents are stakeholders in the discussion, emphasizing the value of their contribution. They are setting the agenda.
- Psychologist discussion groups models how lived experience is shared and valued: it is participatory.

### 2 Post-presentation parent interviews

#### Theme 1: Psycho-social benefits of sharing lived experience

- Parents are not alone.
- Contextualizes TS diagnosis – "what does moderate tics" mean?
- Comparing is healing and connection.
- Normalization of familial experience.
- Benefits of discussing practical application of strategies week to week
- Enables opportunity for family conversations about child's issues.

"I'm not alone, this isn't our own journey, there's lots of other people that are going through a similar journey and that was really comforting for me."

"I think mostly it was kind of normalizing that we're kind of doing it the same as everybody else and that felt good."

"I hate to be relativist about this but in some ways it just makes me think, okay, things aren't as off the rail as maybe I think they are."

"She's allowed to feel her feelings and it just opened up for great conversations between all of us."

"When there's so many people...and it's online, it's really hard for everybody to get an opportunity to speak because then we're also limited to time."

#### Theme 2: Limitations of online group

- Timidity of some parents makes for difficulty in participating, resulting in some participants dropping out.
- Scope of discussion was too broad. Some topics required more attention and time.
- Late scheduling of discussion group was inconvenient.

"People have the option to turn off their camera, you know, but if it was face to face sitting in a circle as a group thing, you wouldn't have that option, right and that eventually you would probably feel compelled to say something."

#### Theme 3: Role of the psychologist

- Importance of psychologist in validating familial experiences.
- Ability of psychologist to impartially create open forum for discussion in which parents feel comfortable is vital.
- Psychologist ability to connect with parents without judgement on them.

"It was nice to have kind of a third party that was unbiased, kind of regulate all of us and, or guide us a bit in a certain direction. She was fantastic in the sense she let us all be ourselves."

"She didn't try to 'should' us, like you should do this or you should do that, she was wonderful and just explored our answers and our questions."

## Conclusions

- Peer group discussion is a vital component in ensuring parents living in geographically large areas connect with other parents, increase their knowledge, and improve family well being.
- The online format is limiting in terms of the extent some parents feel uncomfortable in a relatively large virtual discussion group.
- More time discussing singular aspects/issues of TS and not comorbidities could bring greater depth to parents' knowledge.
- The role of the psychologist moderating the discussion is vital in facilitating the conversation through their expertise and encouraging parents to share and explore their own experiences in a group setting.