



Dear Potential Participant:

This letter is an invitation to participate in a research project I am conducting for my undergraduate thesis at the University of Waterloo. The supervisor for this project is Dr. Diane Williams. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

The goal of this research project is to assess the challenges faced by caregivers as they navigate the health care system in obtaining a correct diagnosis and suitable treatment plan for PANDAS and shed light on the lived experiences of patients' caregivers by responding to the following research questions:

- RQ1. What difficulties have parents faced in receiving treatment since their child was diagnosed with PANDAS?
- RQ2. How has the caregiver's life changed since the abrupt onset of symptoms in their child?
- RQ3. Has the school board, school administration and staff been understanding of their child's condition and the sudden onset of symptoms which may occur?

It is possible that some of the questions I might be asking may be upsetting or unsettling to you. I want you to know that you have the right to pause or stop the interview at any time. You also have the right to not answer questions that you are uncomfortable answering.

Participation in this study is voluntary. It will involve an interview of approximately 30-40 minutes to take place in a mutually agreed upon location and time. The questions will be largely open-ended. You will be asked to consider how your life has changed since your child's PANDAS diagnosis. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time by advising the student researcher. With your permission, the interview will be audio-recorded to facilitate collection of information, and later transcribed for analysis. Your identity will remain confidential. Your name or any other personal identifying information will not appear in the course project paper or any publications resulting from this study; however, with your permission anonymous quotations may be used. The audio recordings collected during this study will be destroyed immediately upon transcription and the transcript from the interview will be retained for the period of at least 10 years in a password protected computer and then destroyed. The consent form that you signed, and your anonymized interviews will be stored in Dr. Williams password-protected.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE# 41672). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca)

For all other questions regarding this study, or if you would like additional information to assist you in reaching a decision about participation, please contact me by email at [akthupi@uwaterloo.ca](mailto:akthupi@uwaterloo.ca) You can also contact my course instructor, Professor Diane Williams, at (519) 888-4567 ext. or email [dianewilliams@uwaterloo.ca](mailto:dianewilliams@uwaterloo.ca)

I very much look forward to speaking with you and thank you in advance for your assistance in this project.

Yours Sincerely,

Altea Kthupi