

INVESTIGATION OF BEHAVIOUR BY DOGS PRIOR TO HUMAN EPILEPTIC SEIZURES AND POTENTIAL UNDERLYING MECHANISMS: EXPERIMENTAL PROTOCOL.

WP1 International inventory of seizure alert dogs:

1. **Title of the study:** Investigation of behaviour by dogs prior to human epileptic seizures and potential underlying mechanisms. Part 1: International Inventory of Seizure Alert Dogs.

2. **Introduction:**

We are a research group from Ghent University (Belgium) investigating whether and how some dogs seem able to detect imminent epileptic seizures.

If you would like to participate, please read this form carefully. If you have any questions, don't hesitate to contact us and we will be more than happy to give you more information about the study and how we use the data.

3. **Study description**

Despite general public interest, the number of seizure alerting dogs across the world is still unknown, particularly the number of dogs who learnt to alert without any training. This international questionnaire aims to compile such a database of alerting and not alerting dogs. We will use it to study possible relationships between the type of seizure, prodromi, aura, etc. and the behaviour of the dog. We hope that this project will be able to provide information that will make it easier to train dogs to accurately predict seizures. Our final goal is to help epilepsy patients by adding predictability to their seizures. In this stage of our research, we are trying to reach as many patients with epilepsy that own a dog as possible.

The survey is aimed to:

- A) People (18-year-old or older) who have been diagnosed with epilepsy
- B) Parents/legal representatives or children (younger than 18-year-old) with epilepsy
- C) Legal representatives of people with learning disabilities than have been diagnosed with epilepsy.

4. Risks and benefits of participating in the study

Participation in this study is completely voluntary.

There are no obvious direct risks for participating in this survey. Nevertheless, you don't need to answer any questions that make you uncomfortable.

While there will be no direct benefit to you, your participation is likely to help us find out more about how some dogs detect and react to seizures. We expect this to have a future impact on the training and acceptance of seizure alerting dogs as reliable aids for epileptic patients.

You will not be provided any economic incentive to take part in the research.

5. Confidentiality

The information you provide in this survey is for our research only and it will be kept private. We will not provide any information about your answers or contact details – should you decide to include them- to any third parties. The information recorded is confidential, your name will not be included in the analysis of the data. The information about you in our analysis will have a number on it instead of your name. Only the researchers will know what your number is and we will secure that information with a lock and key. If you decide to give us your email for further contact, it will only be accessed by the main researcher.

6. Sharing the Results

Nothing that you tell us by filling in the questionnaire will be shared with anybody outside the research team, and nothing will be attributed to you by name. Learning and outcomes from this study will be shared with service dogs trainers and epilepsy support groups. Each participant that so wishes will receive a summary of the results. We will publish some results (again, no information can be traced back to you) so that other interested people may learn from the research.

7. Privacy

This survey is being administered by the University of Ghent using a survey system provided by a third party, SurveyMonkey. Any personal information you submit as part of this survey will be stored and processed by SurveyMonkey on our behalf, in accordance with its Privacy Policy.

8. Ethical committee approval

This study was approved by the Ethical Committee of Ghent University Hospital. In no case should you consider the approval of the Commission for Medical Ethics as an incentive to participate in this study. In accordance with the Belgian law of December 8th, 1992 and the Belgian law of Augustus 22, 2002, we will protect your personal environment and you will be allowed access to the collected data. Any incorrect data can be adjusted on your demand.

Every research is conducted in accordance with the guidelines for good clinical practice (ICH/GCP) which are based on the declaration of Helsinki for protection of individuals who participate in clinical studies.

9. Injury due to participation in the study (only for participants in Belgium)

The researcher provides compensation and / or medical treatment in case of injury due to participation in the study. For this purpose, an insurance has been established with faultless liability in accordance with the Human Experiment Act of May 7, 2004. In this contingency, your information may be passed to the insurer.

10. Who to contact.

For more information or any comments you can contact the main researcher, drs Ana Martos, at this email address: ana.martos@ugent.be or using the following number +32 9-2647818 (Belgian number)

Ana Martos Martinez-Caja

E-mail: ana.martos@ugent.be

Phone: (+32) 09 264 78 18 (In English, Spanish and Italian)

Christel Moons

E-mail: christel.moons@ugent.be

Phone: Tel. (+32) 09 264 78 09 (In Dutch, French and English)