



## LETTER OF INFORMATION

### Evaluating the Impact of a Knowledge Translation Platform for Spinocerebellar Ataxias on its Readers

**Local Principal Investigator:**

Dr. Ray Truant  
Department of Biochemistry  
and Biomedical Sciences  
McMaster University  
Hamilton, ON, Canada  
**(905) 525-9140 ext. 22450**  
E-mail: [truant@mcmaster.ca](mailto:truant@mcmaster.ca)

**Student Investigator:**

Celeste Suart  
Department of Biochemistry  
and Biomedical Sciences  
McMaster University  
Hamilton, ON, Canada  
**(905) 525-9140 ext. 22450**  
E-mail: [scasource@gmail.com](mailto:scasource@gmail.com)

**Student Investigator**

Katherine Graham  
Department of Biochemistry  
and Biomedical Sciences  
McMaster University  
Hamilton, ON, Canada  
**(905) 525-9140 ext. 22450**

**Purpose of the Study**

We would like to invite you to take part in a study on the impact of SCAsource on its readers and their knowledge of research being conducted on spinocerebellar ataxias. Our goal is to determine if SCAsource has helped to improve reader knowledge of ataxia research being conducted and help them feel more connected to ataxia research. Data obtained from these surveys would be used to improve future SCAsource content. Further, it would provide a benchmark for the impact of SCAsource content. By analyzing the impact of SCAsource, we hope to provide a framework for which other rare diseases can launch and evaluate their own knowledge translation websites.

**Procedures involved in the Research**

You will be asked to complete one online survey. This survey is **voluntary and anonymous**, you will be provided a link to complete the survey on LimeSurvey. The link to the survey will be open from September to December 2019. If you wish to participate, please complete the consent module at the beginning of the survey and then fill out the following questions. Survey data will be compiled and analyzed by Celeste Suart and Katherine Graham.

**Potential Benefits**

The research will not benefit you directly. We hope what is learned as a result of this study will help us improve future SCAsource content. This will help us better communicate ataxia research findings to the public. Also, we would like to publish our findings so that other researchers could use this model to create their own knowledge translation website.

**Potential Harms, Risks or Discomforts**

The risks involved in participating in this study are minimal. You may feel uneasy answering questions about your understanding of the material. Please note that your individual responses will not be disclosed. Only compiled cohort data will be released. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable.

**Confidentiality**

You are participating in this research anonymously. No one, including those handling the data, will know that you participated. All electronic data will be kept on a computer protected by a password, where only the research team will have access to it. Once the study is complete, an archive of the data, without identifying information, will be maintained. The electronic data will be kept indefinitely as the data will be published.

**Participation and Withdrawal**

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can stop (withdraw) from the study at any point before submitting your survey responses. Once you have submitted your responses for this anonymous survey, your answers will be put into a database and will not be identifiable to you. This means that once you have submitted your survey, your responses cannot be withdrawn from the study because we will not be able to identify which responses are yours. Your decision whether or not to be part of the study will not affect your continuing access to SCAsource content.

**Information about the Study Results**

We expect to have this study completed by approximately May 2019. If our research article is published, we will make the publication available on the Truant Laboratory Website (<https://raytruantlab.ca/>) and SCAsource (<https://scasource.net/>).

**Questions about the Study**

If you have questions or need more information about the study itself, please contact us at: [truantr@mcmaster.ca](mailto:truantr@mcmaster.ca) or [scasource@gmail.com](mailto:scasource@gmail.com).

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.