



## PATIENT INFORMATION LETTER

### The Spinocerebellar Ataxia-Health Index Phase 2

**Principal Investigator:**

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This form describes a research study that is being conducted by Dr. Chad Heatwole from the University of Rochester Department of Neurology.

The University of Rochester is studying the symptoms and issues that are most important to individuals with spinocerebellar ataxia (SCA). If you are willing to participate, you will have the opportunity to provide your insights about your experience with your disease through the linked survey. The information from this study will ultimately be used to help develop a disease-specific, patient reported outcome measure for clinical trials with individuals with SCA.

If you are willing to participate in this research, you may do so by clicking the link and completing the survey. The survey will take approximately 20-30 minutes to complete, and all responses will be strictly confidential. Your survey responses will be completely anonymous.

The survey contains some personal questions about you and about the specific symptoms that have the greatest impact on your life. The symptoms included in this survey were previously identified as important through interviews with individuals with SCA. If possible, we would like you to complete the entire survey, but you may skip any questions that you do not feel comfortable answering. If you prefer, the survey can also be completed on paper or over the phone. If you prefer either of these methods, please contact the study coordinator, Preshetha Kanagaiah, at (585) 210-2563 or [Preshetha.kanagaiah@chet.rochester.edu](mailto:Preshetha.kanagaiah@chet.rochester.edu).

Some of the survey questions may be upsetting or make you feel uncomfortable. You can skip any of the questions you do not want to answer. Because this study involves collecting your health information, there is a potential for invasion of privacy or breach in confidentiality. To minimize this risk, your survey responses will be anonymous. We will not store any directly identifiable information that we are using to contact you with your survey responses. All of the information that we collect will be stored in a secure manner, and only study team members will have access to it. There are no other expected risks. There are also no expected benefits.

You will receive no direct benefit from participating in this study. You will not be paid, and there are no expected costs for you to participate in this study. The University of Rochester and investigators of this study may or may not receive licensing fees through the eventual development of the SCA-Health Index (SCA-HI). You will not receive any of this benefit.

### **Confidentiality of Data**

The University of Rochester makes every effort to keep the information collected from you private. In order to do so, your survey responses will be anonymous. Survey data will be stored indefinitely. All study data will be stored in a secure manner and accessible only to the study team. Sometimes, however, researchers need to share information that may identify you with people that work for the University or regulators. If this does happen, we will take precautions to protect the information you have provided. Results of the research may be presented at meetings or in publications, but your name will not be used.

In order to collect study information, we have to get your permission to use and store your health information. Your name and other personally-identifiable information will NOT be included in the survey data. Your permission to use your anonymous health information for this study will not expire. We will keep the anonymous information we collect about you indefinitely.

**Participation in this study is voluntary.** You are free to not to participate or withdraw at any time, for whatever reason, without penalty or loss of benefit to which you are entitled. In the event that you do withdraw from this study, the information you have already provided will be kept in a secure manner. For more information or concerns regarding this research, please contact Preshetha Kanagaiah at [Preshetha.kanagaiah@chet.rochester.edu](mailto:Preshetha.kanagaiah@chet.rochester.edu) or (585) 210-2563.

Please contact the University of Rochester Research Subjects Review Board at 265 Crittenden Blvd., CU 420628, Rochester, NY 14642, Telephone (585) 276-0005 or (877) 449-4441 for the following reasons:

- You wish to talk to someone other than the research staff about your rights as a research subject;
- To voice concerns about the research;
- To provide input concerning the research process;
- In the event the study staff could not be reached.

Thank you for your interest and your time!