**Informed Consent Form with Assent**

**Research Project title**: Discourse in Persons with Right Hemisphere Brain Damage (RHD)

**Primary investigator**: Melissa Johnson, Ph.D., CCC-SLP, Associate Professor, Department of Communication Sciences and Disorders, (585) 389-4412, [mjohnso2@naz.edu](mailto:mjohnso2@naz.edu)

**Additional investigators**: Ciara Costley, B.S., Graduate Assistant

1. **Purpose of the Research**: The purpose of this research is to determine patterns and distinguishing characteristics of language and discourse in people with right hemisphere brain damage (RHD) from a stroke. Videos and transcripts will be placed in a shared computerized database in order to allow for comparisons to other people with RHD. This study has been reviewed and approved by the Human Subject Research Committee at Nazareth College.
2. **Description of Procedures**: During this research, I will be asked to describe pictures, discuss events in my life, tell a story, and other similar types of talking tasks. I will also complete a hearing questionnaire, and a standardized measure of language and cognition (the Cognitive-Linguistic Quick Test). The session will be videotaped for later transcription and analysis. In addition, I will be asked to provide relevant demographic information.
3. **Duration of Procedures**: The research will take approximately 1.5 - 2 hours of my time and will be completed at the York Wellness and Rehabilitation Institute or via the electronic platform Zoom. If my appointment is in person, all appropriate COVID-19 precautions (i.e., all participants masked, surfaces and materials cleaned before and after use, windows open if able) will be employed, if they are still needed.
4. **Risks and Discomfort**: There are no anticipated possible risks or discomfort in participating in this research. As in all research, there may be unforeseen risks to the participant. If an accidental injury occurs, appropriate emergency measures will be taken.
5. **Benefits:** There is no direct benefit to participate in this study.
6. **Statement of Participation**: I must be 18 years old to participate in this study. Participation in this project is voluntary. I will not be paid for the participation. I may withdraw and discontinue participation at any time without penalty or loss of benefits.
7. **Statement of Confidentiality**: Participation in this research is confidential. Neither my name nor any information that may identify me will be used in any reports or transcripts. My confidentiality will be maintained in the following manner:

* My videos and other data will be kept separate from my consent form. My consent form will be stored in a locked location on Nazareth College property and will not be disclosed to third parties.
* The videos, data, and information gathered during this study may be used by Nazareth College and published and/or disclosed by Nazareth College to others outside of Nazareth College. However, my name, address, contact information and other direct personal identifiers in my consent form will not be mentioned in any publication or dissemination of the research data and/or results.
* My videos will be uploaded in an unedited form. This means that my voice and face will be visible to viewers. However, my name and other identifying information will not be available to researchers or viewers.
* My videos, verbatim transcripts, and data will be uploaded to a shared database (rhd.talkbank.org), allowing authorized researchers and educators from other institutions to view them, analyze them, and compare them to others’ data. The researchers will take the following steps to protect my identity: (1) All research data will be assigned a participant code; (2) The researchers will record any data collected during the study by participant code, not by name; (3) Original recordings and data files will be stored in a secured location accessed only by authorized researchers; (4) Access to the audio and video files and language transcript database is password protected, accessed only by authorized researchers and TalkBank members.
* If the session is conducted via Zoom, the waiting room will be enabled to ensure that no unauthorized individuals can enter the session.

1. **Contacts for questions**: For any questions or concerns regarding this study, I may contact the primary investigator (see above contact information).I may also contact Elizabeth Hebert (585-389-2071) or Cathy Leverone (585-389-5074), the Co-Chairs of the Human Subjects Research Committee at Nazareth College, if questions or problems arise during the course of the study*.*

I have read and understand the information provided. I voluntarily agree to participate in this study.

Participant Signature Date



Researcher Signature Date

**Adult Assent**

If I cannot give legal consent to take part in this study because I have trouble reading or understanding this consent form, then the researcher will ask for my assent. Assent is my agreement to be in the study. The researcher will explain the study to me in words that I can understand. I will ask questions about anything I don't understand. Then I will decide if I want to be in the research study. If I want to participate, I will sign the form or make my mark, if able. Someone who can sign a legal document for me must also give their permission and sign this form before I take part.

By signing below, I agree to participate in this study:

Participant Signature Date

**Consent of Guardian /Representative:** If you have authority to consent on behalf of the above named participant, please print your name \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ and indicate your relationship to the participant:

\_\_\_\_\_ The participant's legal guardian

\_\_\_\_\_ A surrogate

\_\_\_\_\_ A durable power of attorney

\_\_\_\_\_ A proxy

\_\_\_\_\_ Other, please explain: \_\_\_\_\_\_\_\_\_ \_

By signing below, you warrant that you have the authority to make decisions on behalf of the participant. You agree that the above information has been explained to you and all your current questions have been answered. You understand that you may ask questions about any aspect of this research study during the course of the study and in the future. By signing below, you consent to the participant's involvement in this study.

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Signature of Legally Authorized Representative Date

I certify that I have explained the nature and purpose of this research study to the above individual and I have discussed the potential benefits and possible risks of participation in the study. Any questions the individual has about this study have been answered and any future questions will be answered as they arise.

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Signature of Person Obtaining Consent Date