

## University of Maryland College Park

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Initials \_\_\_\_\_ Date \_\_\_\_\_

<b>Project Title</b>	Voices of people who stutter/clutter (Teaching with FluencyBank)
<b>Purpose of the Study</b>	<p><i>This research is being conducted by Professor Nan Bernstein Ratner at the University of Maryland, College Park. We are inviting you to participate in this research project because you are an adult who stutters or has a fluency disorder. The overarching goal of our research is to identify the behavioral, cognitive and affective features that distinguish fluency disorders such as cluttering or stuttering and more typical disfluency seen in first and second language learners. The purpose of this research project is to document behavioral, affective and cognitive components of fluency disorder in adults. These videos would also be accessible by university instructors and students in order to better prepare them to provide optimally informed and sensitive care to their clients.</i></p>
<b>Procedures</b>	<p><i>The procedures involve answering a series of 6 questions, while you are video-taped; the video would then be posted to a password protected internet site at the new FluencyBank project (at <a href="http://www.Talkbank.org">www.Talkbank.org</a>). In addition, we will ask you to complete a very commonly used questionnaire (the OASES) designed to appraise the affective and cognitive consequences of living with a fluency disorder. Upon entry into this project, you will be assigned a number, which will be used to link your videotaped interview to your OASES form.</i></p> <p><i>We will also ask you to read a short passage from the Stuttering Severity Instrument (SSI-4). This should take less than 2 minutes.</i></p> <p><i>The specific questions you will be asked are:</i></p> <ol style="list-style-type: none"><li><i>1. Please talk about the impact of stuttering on your daily life: You can talk about your interactions with family and friends, school and/or work, and your participation in community activities.</i></li><li><i>2. What do you think causes stuttering?</i></li><li><i>3. If you have received treatment for your stuttering, tell me about your therapy experiences and the outcomes of these therapies.</i></li><li><i>4. Please describe what successful communication means to you; can you give an example of a positive communicative experience?</i></li><li><i>5. If you didn't stutter, what might be different in your life?</i></li><li><i>6. What else would you want to say to students (or the general public) to help them learn about stuttering or ways to support people who stutter?</i></li></ol> <p><i>You may choose not to answer some of these questions. You will be allowed to spend as much time as you like answering each or all of these questions. You may choose not to complete the OASES form. We will be video-recording your interview questions for posting. We will allow you to review your videotaped interview before posting and request edits or non-contribution of your interview and OASES form. At any point, you may</i></p>

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	<p><i>notify FluencyBank in writing or by email if you would like us to remove your video and/or OASES form from the Fluency Bank site; you do not have to provide us with any reason for your request to remove your contributions.</i></p>
<b>Potential Risks and Discomforts</b>	<p><i>There may be some risks from participating in this research study. The primary risk is that a person who attains access to the site may identify you as a person who stutters, and may identify your treatment history. If you perceive any risk or discomfort from your contribution, you have the ability to remove your data from the FluencyBank at any point.</i></p>
<b>Potential Benefits</b>	<p><i>There are no direct benefits from participating in this research. However, possible benefits include better preparation of clinicians in training to work with people who stutter or who have other fluency disorders. We hope that, in the future, other people might benefit from this study through improved understanding of the complexities of fluency disorder and can use the data from FluencyBank to improve research, clinical education and advocacy for people with fluency disorders.</i></p>
<b>Confidentiality</b>	<p><i>Because your contributed sample is videotaped, it is possible that a user of the Fluency Bank may recognize you, even though your name will not be posted with either your video interview or survey. Any potential loss of confidentiality will be minimized by assigning you a number. The linkage between this participant number and your consent form information will be maintained in a secure location (locked files, encrypted files) by the PI (Ratner) at the University of Maryland. Only individuals supervised by Dr. Ratner will have access to these data, for the purposes of transcription for Bank use.</i></p> <p><i>If we write a report or article about this research project, your identity will be protected to the maximum extent possible. Your information may be shared with representatives of the University of Maryland, College Park or governmental authorities if you or someone else is in danger or if we are required to do so by law.</i></p> <p><b><i>YOU MAY REQUEST REMOVAL OF YOUR MATERIALS FROM THIS SITE AT ANY TIME BY CONTACTING THE PI:</i></b></p> <p><b><i><u><a href="mailto:nratner@umd.edu">nratner@umd.edu</a></u></i></b></p>
<b>Compensation</b>	<p><i>You will NOT be compensated for your participation in this project.</i></p>
<b>Right to Withdraw and Questions</b>	<p><i>Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.</i></p> <p><i>If you decide to stop taking part in the study, if you have questions, concerns, or complaints, or if you need to report a concern related to the research, please contact the investigator:</i></p>

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	<p><b>Nan Bernstein Ratner, Professor</b> Department of Hearing and Speech Sciences 0100 Lefrak Hall University of Maryland, College Park, MD 20742 301-405-4217, <a href="mailto:nratner@umd.edu">nratner@umd.edu</a></p>	
<b>Participant Rights</b>	<p><i>If you have questions about your rights as a research participant or wish to report a research-related injury, please contact:</i></p> <p style="text-align: center;"><b>University of Maryland College Park Institutional Review Board Office 1204 Marie Mount Hall College Park, Maryland, 20742 E-mail: <a href="mailto:irb@umd.edu">irb@umd.edu</a> Telephone: 301-405-0678</b></p> <p><i>This research has been reviewed according to the University of Maryland, College Park IRB procedures for research involving human subjects.</i></p>	
<b>Statement of Consent</b>	<p><i>Your signature indicates that you are at least 18 years of age; you have read this consent form or have had it read to you; your questions have been answered to your satisfaction and you voluntarily agree to participate in this research study. You will receive a copy of this signed consent form.</i></p> <p><i>If you agree to participate, please sign your name below.</i></p>	
<b>Signature and Date</b>	<b>NAME OF PARTICIPANT</b> [Please Print]	
	<b>SIGNATURE OF PARTICIPANT</b>	
	<b>DATE</b>	Email contact: