

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researchers or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

I am asking you to participate in a research study titled "Alice in Wonderland/Todd's Syndrome". I will describe this study to you and answer any of your questions. This study is being led by Daniel Mei.

What the study is about The purpose of this research is to get an insight into the lives of people who have Alice in Wonderland/Todd's Syndrome, and have their opinions and voices heard.

What we will ask you to do I will ask you to answer a series of questions pertaining to your experiences with Alice in Wonderland/Todd's Syndrome, and how it has affected your life.

Risks and discomforts

- Emotional risks (e.g., feelings of sadness or anxiety)

Benefits

No direct benefit given to individuals participating in study. Information you provide will hopefully voice concerns about Alice in Wonderland/Todd's Syndrome, and hopefully will raise more awareness to the medical community.

Compensation for participation

No compensation given for participation to participants.

Audio/Video Recording

Audio Recording will be used in-case I need to look back at an interview for future use during the study. All recordings relevant to the study will be promptly erased and destroyed on or before 6/1/2020. And will not be used for any purpose besides this specific study being conducted.

Please sign below if you are willing to have this interview's audio recorded. You may still participate in this study if you are not willing to have the interview recorded.

I do not want to have this interview recorded.

I am willing to have this interview recorded:

Signed: _____

Date: _____

Privacy/Confidentiality/Data Security

All Identifying information will be removed and replaced with filler names for confidentiality. Only I will have access to all information in the study pertaining to the identity of the individual. Due to the nature of interviews taking place through calls, text, or email (depending on participants preference), there is a possibility of identifiable information being known, however I anticipate that your participation in this survey presents no greater risk than everyday use of the Internet.

**Please note that email communication is neither private nor secure. Though I am taking precautions to protect your privacy, you should be aware that the information sent through email could be read by a third party. As well as data possibly existing on backups and server logs beyond the timeframe of this research project if call or text is used.*

Sharing De-identified Data Collected in this Research

De-identified data from this study may be shared with the research community at large to advance science and health. We will remove or code any personal information that could identify you before files are shared with other researchers to ensure that, by current scientific standards and known methods, no one will be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Future use of Identifiable Data or Specimens Collected in this Research

Your information or biospecimens will not be used or distributed for future research studies.

Taking part is voluntary

Since your involvement is voluntary, you may refuse to participate before the study begins, discontinue at any time, or skip any questions/procedures that may make you feel uncomfortable, with no penalty to you, and no effect on the compensation earned before withdrawing, or their academic standing, record, or relationship with the university or other organization or service that may be involved with the research.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, please contact me

Name: Daniel Mei

Phone Number: 330-734-8239

Email: danielmei2021@gmail.com

**Please feel free to make copies of this form*

Statement of Consent(Participant)

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true. I freely give my consent to take part in this study and authorize that my health information as agreed above, be collected/disclosed in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Consent(Researcher)

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he/she understands: What the study is about; What procedures/interventions/investigational drugs or devices will be used; What the potential benefits might be; and What the known risks might be. I can confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in the appropriate language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical/psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

Signature of Person Obtaining Informed Consent / Research Authorization

Date

Printed Name of Person Obtaining Informed Consent / Research Authorization