

# Permission to Take Part in a Human Research Study

## Georgetown University

**Key Information:** The following is a short summary of this study to help you decide whether or not to be a part of this study. More detailed information is listed later on in this form.

### ***Why am I being invited to take part in a research study?***

We invite you or your family member to take part in a research study because of the rarity of his or her condition that we would like to write a report on and publish in literature.

### ***What should I know about a research study?***

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

### ***Why is this research being done?***

The purpose of our research is to report on the course, diagnostic methods, and treatment options of this rare conditions to aid others in managing this serious condition

### ***Will being in this study help me anyway?***

Though this study may not benefit you directly, we hope that publishing this information will aid other patients with this condition in the future by reporting our experience in managing, diagnosing, and treating this condition

### ***What happens if I do not want to be in this research?***

Participation in research is completely voluntary. You can decide to participate or not to participate.

### ***Who can I talk to?***

If you have questions, concerns, or complaints, or think the research has hurt you, talk to the research team (Dr. Alexander Dao @ [Alexander.e.dao@gunet.georgetown.edu](mailto:Alexander.e.dao@gunet.georgetown.edu))

### ***What happens to the information collected for the research?***

Efforts will be made to protect your medical records and other personal information to the extent allowed by law. However, we cannot guarantee absolute confidentiality. Records of research study participants are stored and kept

You will not be identified in any reports or publications resulting from this study.

### Signature Block for Capable Adult

Your signature documents your permission to take part in this research.

Phone consent obtained (202-468-2207)

\_\_\_\_\_  
Signature of subject

1/8/2019

\_\_\_\_\_  
Date

[REDACTED]  
Printed name of subject

[REDACTED]  
Signature of person obtaining consent

1/8/2019

\_\_\_\_\_  
Date

[REDACTED]  
Printed name of person obtaining consent

My signature below documents that the information in the consent document and any other written information was accurately explained to, and apparently understood by, the subject, and that consent was freely given by the subject.

[REDACTED]  
Signature of witness to consent process

1/8/19

\_\_\_\_\_  
Date

[REDACTED]  
Printed name of person witnessing consent process

**Signature Block for Capable Adult**

Your signature documents your permission to take part in this research.

Phone consent obtained from daughter Jamie Garity (304-643-1622) 1/8/2019  
Signature of subject Date

Anna Garity (patient, deceased), Jamie Garity (POA, daughter)  
Printed name of subject

[Redacted Signature]  
Signature of person obtaining consent  
1/8/2019  
Date

[Redacted Name]  
Printed name of person obtaining consent

My signature below documents that the information in the consent document and any other written information was accurately explained to, and apparently understood by, the subject, and that consent was freely given by the subject.   

[Redacted Signature]  
( ) Signature of witness to consent process  
1/8/2019  
Date

[Redacted Name]  
Printed name of person witnessing consent process