

## Assent Form (Ages 7 – 11)

**Study Title: Genetic Studies of Constitutional Disorders**

**Study number: AAAS7948**

**Anticipated number of Subjects:**  
13,500

**Study duration: 1 hour**

**Principal Investigator: Dr. Ali Gharavi**

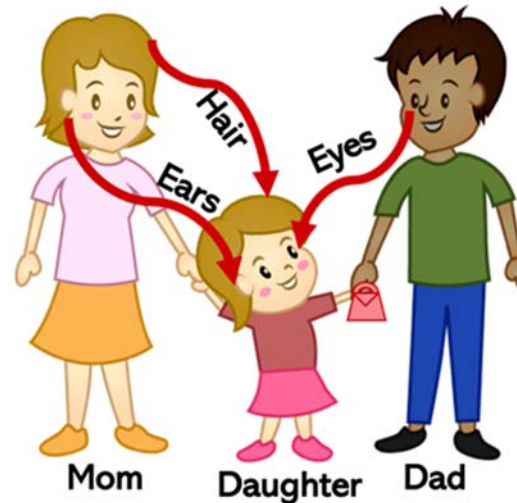
**Contact number: 212-851-4927**

**Email: [cpmq\\_info@cumc.columbia.edu](mailto:cpmq_info@cumc.columbia.edu)**



### 1. Why are we doing this study?

We are asking you to be in a research study. Research is a way to test new ideas. Research helps us learn new things. In this study, Dr. Gharavi and his helpers want to learn more about what causes sickness and why some sicknesses may run in families.



### 2. What is a genetic study?

A genetic study looks at a person's DNA. A person's DNA has information that tells their body how to work. Sometimes a person has a difference in their DNA that causes their body not to work correctly and might cause them to become sick. We want to find out what kind of differences cause people to become sick.

Learn more about genetics:

<https://www.amnh.org/explore/ology/genetics/what-s-the-big-idea-about-genetics2>

### 2. Procedures (What will happen?)

If you agree to be in this study, you will be asked to do the following:

- ~ Answer some questions.
- ~ Give a sample of your DNA. We will probably do this by drawing blood from your arm.
- ~ We will also ask you and your parent if you are willing to come back to see us, let us know how you are feeling, and give other samples.
- ~ We might learn information about your DNA. This information could change how your doctors care for you. If we find this information, you and your parent have the choice of learning or not learning what we found.

You can ask as many questions as you like about the study and Dr. Gharavi or his helpers will explain it to you in a way that you can understand.

### 3. Benefits (How may it help you?)

Sometimes things happen to people in research studies that make them feel good or benefit them in some way. A "benefit" is something good or helpful. There are many different ways research can benefit people: feeling better, new medicine, or having new information you did not know before.

There is no direct benefit to you from being in this study, but the results may help us learn more about why children your age develop certain sicknesses.

We will use this to help children and families with sicknesses in the future.

#### 4. Risks (Will it hurt?)

In this research study, it may hurt when the needle is put in your arm to take blood. You will feel a tiny pinch and your arm may feel sore for a few minutes.

#### 5. Privacy (Who will know about it?)

We will keep your information such as your name and your birthday (private information). We will use it to do research into why people have conditions like yours. Some information that we get from you may also be shared with other helpers in a different research study. We do not share your name and birthday so they will not know who you are.

When we are finished with this study we will write a story about what we learned. This story will not include your name or that you were in the study.

#### 7. Do I Have To Be In This Study?

No, you don't have to be in this study. It's up to you. No one will be upset with you if you don't want to participate. If you say yes now, you can still change your mind later if you want to stop. Please talk to your parents about the study before you decide.

#### 8. What will happen when I turn 18 years old?

When you turn 18 years old, we will contact you and ask you to agree to continue participating in this study again and sign the form your parent signed today.

#### 9. Can I ask questions?

Yes, you can ask any question at any time. You can ask now or later. You can talk to your doctor and your parents if you are not sure about something. You can call us at 212-851-4927 or email us at [cpmg\\_info@cumc.columbia.edu](mailto:cpmg_info@cumc.columbia.edu), or ask your parent to contact us at any time if you have more questions about the study. This form is yours to keep.



#### STATEMENT OF ASSENT

If you say YES to be in this research study, please sign below. If you do not want to be in this study, do not sign this paper.

#### Child Study Participant

\_\_\_\_\_  
Print name of Child

\_\_\_\_\_  
Signature of Child

Signature Date \_\_\_\_/\_\_\_\_/\_\_\_\_

#### Person Obtaining Assent

\_\_\_\_\_  
Print name of Person Obtaining Assent

\_\_\_\_\_  
Signature of Person Obtaining Assent

Signature Date \_\_\_\_/\_\_\_\_/\_\_\_\_