



**The Montalcino Aortic Consortium:  
Precision Medicine for Heritable Thoracic Aortic Disease  
HSC- MS-16-0191  
ADOLESCENT/ASSENT FORM TO TAKE PART IN RESEARCH  
Minors Age 7-17 years**

**INVITATION TO TAKE PART IN A RESEARCH STUDY**

Dr. Dianna Milewicz is inviting you to take part in a research study. You need to know about the study so you can decide if you would like to join the study or not. If you enter the study you will be asked to sign this form. You may take time to think or talk with your family before making your decision. Your parent(s) or legal guardian will also be asked to give their permission for you to take part in this study.

**WHY IS THIS STUDY BEING DONE?**

We are inviting you to take part in this study because we are trying to learn more about conditions that can cause blood vessel and related health problems. Both adults and children will be in this study. The information collected from them will help find better ways to treat people affected with these problems in the future.

**WHAT WILL HAPPEN IF YOU JOIN THE STUDY?**

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

- You will be asked to give permission for records from your doctors to be shared with this study. This information may be shared with other researchers but will not have your name or other information used to identify you.
- You may be asked to provide a photograph of the face or other parts of the body. You may refuse photographs of any part that you are uncomfortable having photographed.
- You may be asked to provide a saliva or blood sample. Your sample will be kept in the study until they are gone. Your sample and information collected from testing of your sample may be shared with other researchers but it will not have your name.
- You may be contacted in the future to request new information, to ask you to answer a survey or tell you about new studies that you can join.
- You will be contacted when you turn 18 years old to ask your permission to continue taking part in the study.

**WHAT ABOUT SAMPLES THAT ARE COLLECTED FOR FUTURE RESEARCH?**

If you gave a DNA, saliva or blood sample to the study, we will ask that you re-approve the use of your samples for other research in the future.

**WHAT ARE THE BENEFITS TO TAKING PART IN THIS STUDY?**

Taking part in this study may or may not help you. Information from this study might help researchers to come up with new tests, medications or treatments to help you and others with the same health conditions in the future.

**WHAT ARE SOME OF THE RISKS AND DISCOMFORTS? WHAT COULD HAPPEN THAT NO ONE WOULD LIKE?**

If a blood sample is taken from you, there is a small risk of physical harm like mild pain, bruising, infection, or feeling of lightheadedness.

Although we will take measures so that your personal and medical information will not be shared with people who are not part of the study, there is a small risk that your information may be obtained by individuals who are not related to the study and used for reasons outside of this project.

**CAN YOU STOP BEING IN THE STUDY?**

Your parent(s) or legal guardian must give permission for you to take part in this study, but you can choose if you want to be in this study or not. No one will be mad at you if you do not want to be in the study. If you decide to be in the study, you can stop at any time.

**IS THERE A COST TO BE IN THE STUDY?**

There is no cost to take part in the study. You will not be paid to take part in the study.

**WHO WILL KNOW YOU ARE IN THE STUDY?**

When researchers are working on a research project like this, everything you say and everything they write down is private. When anything is written down about you, a special number is written instead of your name. The list and codes of names are kept in a secure locked file that can only be seen by Dr. Milewicz and allowed study personnel.

**WHAT IF YOU HAVE ANY QUESTIONS?**

You can ask questions any time. You can ask now or you can ask later. You can talk to the study doctor or you can talk to someone else. If you would like to contact the research doctor, she can be contacted at 713-500-6715.

**SIGNATURES:**

Sign this paper if you understand the study and if you decide you want to join the study. Remember that you can always change your mind and stop taking part in the study by telling your parents or anyone working in this study. A copy of this form will be given to you and your parents.

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Printed Name of Subject

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Signature of Subject

Date

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Printed Name of Individual Obtaining Consent

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Signature of Individual Obtaining Consent

Date

***CPHS STATEMENT:***

This study (HSC-MS-16-0161) has been reviewed by the Committee for the Protection of Human Subjects (CPHS) of the University of Texas Health Science Center at Houston. For any questions about research subject's rights, or to report a research-related injury, call the CPHS at 713-500-7943.