

Approved by the Nemours IRB: Valid from: 02/16/2015 through 02/15/2016 IRBnet 83142 V 2-2015

Abbreviated Study

Title: Primordial Registry at A.I. duPont Hospital for Children

## ADOLESCENT ASSENT FORM FOR YOUTH AGES 12 -17

Your parent has given permission for you to be in a project called a research study. But first, we want to tell you all about it so you can decide if you want to be in it. If you don't understand, please ask questions. You can choose to be in the study, not be in the study or take more time to decide.

1. What is the name of the study?  
Primordial Registry at A.I. duPont Hospital for Children
2. Who is in charge of the study?  
The doctor in charge of the study is Dr. Bober
3. What is the study about?  
We would like to learn more about people with primordial dwarfism by comparing their medical records. We hope that we can find things that people have in common so that better treatments can be found in the future.
4. Why are you asking me to be in this study?  
You are being asked to be in the study because you have primordial dwarfism or a related condition.
5. What will happen to me in the study?  
You do not have to do anything extra to be in this study. You will be seen by your regular doctors and will only have tests that they need to run so that they can take care of you. The study team would like permission to look at your medical records. The study team will not ask you to have any testing done just for the study.  
  
There is a small chance that someone who is not working on the study will see your research records and use them for some other purpose. Dr. Bober and his staff will do what they can to keep this from happening.
6. Will I be paid to be in this study?  
You will not be paid for being in this study.

