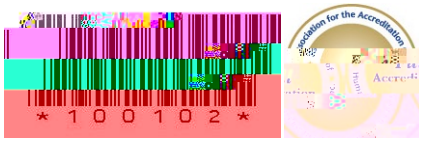
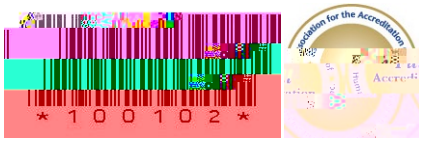


Approved by the Nemours IRB: Valid from: 02/16/2015 through 02/15/2016 IRBnet 83142 V 2-2015

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

Nemours
Informed Consent for Participation in an Observational / Non-Interventional Research Study

You have been asked to be in a research study. This form explains the research, your rights as a3d 0.094 Tw/ 67



5. WHO IS SPONSORING OR PAYING FOR THE STUDY?

The Potentials Foundation is a sponsor of this study, by ensuring that all participants will have no cost associated to mailing information to Nemours. If needed, a pre-paid mailing envelope can be forwarded to participants by a representative from the Potentials Foundation.

6. WHO CAN BE IN THE STUDY?

Individuals with MOPDII, MOPDI/III, Meier-Gorlin syndrome, and unclassified or closely related forms of microcephalic primordial dwarfism as diagnosed by a physician are eligible for this registry.

7. HOW MANY OTHER PEOPLE WILL BE IN THE STUDY?

Approximately 100 individuals with MOPDII (and/or other forms of primordial dwarfism) will be enrolled in the study.

8. HOW LONG WILL PARTICIPATION IN THE STUDY LAST?

This study is limited to chart review. There will be no additional visits or time in clinic because of your participation in this registry. The study team believes participation will last for at least 5 years.

9. WHAT ARE THE RESEARCH PROCEDURES?

This study involves only the collection and storage of data extracted from the medical record. There are no special procedures, visits, or expectations of you as a result of participation in this registry. You will not be asked to have any specific testing for the sole purposes of research.

<u>Patient at AIDHC</u>

If you have had lab work or imaging studies performed at AIDHC these records may be reviewed to gain additional information about this disease. Records that may be reviewed as a part of this study include but may not be limited to x-rays of teeth and other bones, results of routine blood and urine tests, results of genetic testing and neurovascular imaging (images of blood vessels in the brain).

<u>Patient outside of AIDHC</u>

You may have heard about this study by viewing information at the Potentials Foundation website

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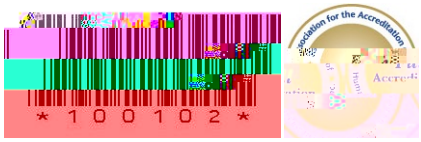

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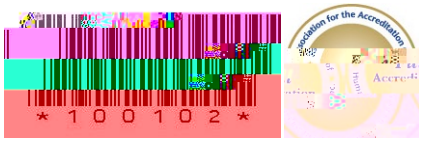
13. WHAT ARE THE COSTS OF BEING IN THIS STUDY?

There are no direct costs to families for participating in this registry if you are a patient at Alfred I duPont



- x The use and / or disclosure of my PHI will stop after Nemours receives the withdrawal notice. Information that is used or disclosed before the withdrawal may still be used.
- x Unless I withdraw consent, the use and / or disclosure of my PHI described in this form will not have an expiration date.
- x My PHI may be disclosed again by the person or organization (other than Nemours) that receives it. If this happens, Federal or state law may not protect the information.
- x I have the right to refuse to sign this permission form.
- x If I refuse to sign this consent form, I will not be allowed to be in this research study.
- x I have the right to ask Nemours to tell me who has received my protected health information.
- x I have the right to revoke my permission for the use and disclosure of my health information at any time, which would end my participation in this study.
- x I will receive a signed and dated copy of this form.

My signature indicates that:

- x I give my consent to participate in the research study described in this form.
- x I give the researchers and Nemours permission to use and /or disclose my individually identifiable health information for this research study as described in the section on use and disclosure of PHI.

Name of Participant (**Print)** Date

Signature of Participant Date

I the undersigned, certify that to the best of my knowledge the participant signing this informed consent form had the study fully and carefully explained and that he / she understands the nature, risks and benefits of participation in this research study.

Name of Person Obtaining Permission (**Print**)
(Investigator or Designee)

Signature of Person Obtaining Permission
(Investigator or Designee) Date

A copy of the signed form was provided to Participant ☐ Date