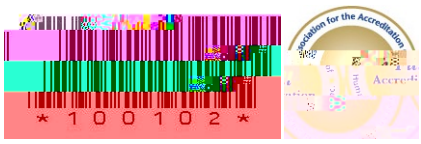

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Abbreviated Study Title: Primordial Registry at A.I. duPont Hospital for Children

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team hopes to learn more about this illness and improve the care of people with it by establishing this registry.

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 all participants by a representative from the Potentials Foundation.

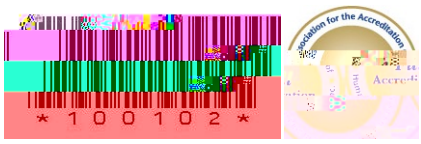
6. WHO CAN BE IN THE STUDY?
   Individuals with MOPDII, MOPDI/III, Meier-Gorlin syndrome, and unclassified or closely related forms of microcephalic primordial dwarfism as diagnosed by a physician are eligible for this registry.

7. HOW MANY OTHER PEOPLE WILL BE IN THE STUDY?
   Approximately 100 individuals with MOPDII (and/or other forms of microcephalic 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 child's 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 your child as a result of participation in this registry. Your child will not be asked to have any specific testing for the sole purposes of research.

   Patient at AIDHC
   If your child has had lab work or imaging studies performed at AIDHC these records may be reviewed to gain additional information about this condition. 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).
   Patient outside of AIDHC
   You may have heard about this study by viewing information at the Potentials Foundation website (www.PotentialsFoundation.org), Walking with Giants Foundation (www.walkingwithgiants.org), Geneclinics.org, or the Skeletal Dysplasia program site within the Nemours organization website (9tese.002 Tc 0.p7(i)3(ne bl)(),)Tj ll]TJ 0entialania11(r)-6( )11(t)- lpe14(ec(i)3(t-7(s)-2(,tds)-2( )11(t 44N)3(e)11(m)-7



Alfred I duPont Hospital for Children
Medical Genetics
1600 Rockland Road
Wilmington, DE 19803

302-651-5916

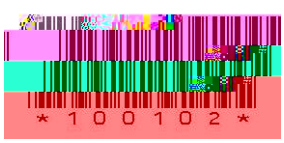
Items mailed:
1 copy of informed consent with original signature
1 copy of medical release form with original signature
Medical records
Medical images (x-ray and/or MRI)

By agreeing to be in the registry, you allow study team members to review your child's medical records and collect information about their illnesses.

10. WHAT ARE POSSIBLE RISKS OF BEING IN THIS STUDY?

The risks involved in this study are the same as the risks your child would ordinarily encounter in daily life. This research is observational which means that there is no change to any treatment that your child may be receiving. The most common risk of participation in a registry is the chance that your child's private information (ex: insurance coverage, status of health, treatments prescribed) may be used for purposes other than those described in this permission form. Loss of privacy may affect your child's insurability, employability or may result in labeling of a person with a chronic illness. The protection of your child's confidential information is further described in Section 16 of this form.

Genetic Research



13. WHAT ARE THE COSTS OF BEING IN THIS STUDY?
    There are no direct costs to families for participating in this registry. Costs related to your child's regular care will still be your or your child's insurance company's responsibility.

14. WILL MY CHILD BE PAID FOR BEING IN THIS STUDY ?
    Participants will not be paid for participating in this study. No arrangement exists that would allow participants to share in any profit generated from this study or future research.

15. WILL I BE TOLD OF ANY NEW INFORMATION THAT MIGHT AFFECT MY WILLINGNESS TO PERMIT MY CHILD TO STAY IN THE STUDY?
    Any new information that may change your mind about allowing your child to be in this study will be given to you. A committee called the Institutional Review Board (IRB) will review this study at least once per year. If the IRB finds that there is new information that you should know about while your child is taking part in this study, it will ask the study doctor to tell you about it. You may be asked to sign a new version of this form after discussing the new information with a member of the research team.

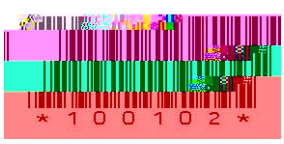
16. WHAT INFORMATION ABOUT MY CHILD WILL BE USED OR DISCLOSED? (AUTHORIZATION TO USE AND / OR DISCLOSE PROTECTED HEALTH INFORMATION)
    Identifiable health information about your child will be used by Nemours researchers and may be given to people outside of Nemours for this research. This is done to conduct the research study, to monitor the safety of research participants and for auditing. Federal law requires us to tell you about, and get your approval for research use and disclosure of health information that includes "identifiers" that can connect the health information to your child. (Names, initials, date of birth, addresses, phone numbers, and social security numbers are examples of identifiers.) This Identifiable health information is called Protected Health Information (PHI).

    Use of Health Information by Nemours Staff
    The health information that will be used within Nemours includes all data collected for this study, as described in Section called "What Are the Research Procedures?"

    Your child's identity will be protected as much as possible. Nemours protects you and your child's health information by storing records in files or computers that can only be used by authorized Nemours staff.

    The people within Nemours that may use this health information include:
    - The investigators listed on the first page of this permission form and their staff,
    - The Nemours Institutional Review Board (IRB) (The IRB is a group of people that reviews research activities. The IRB is responsible for the safety and rights of research participants), and;
    - Nemours internal audit staff.

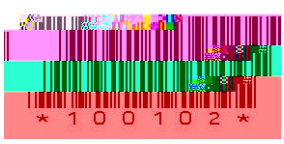
    Disclosure of Health Information to Others
    Identifiable health information will be disclosed (given) to the following individuals or groups:
    - Carol Wise, PhD, Co-Investigator (Genetics, Texas Scottish Rite Hospital for Children)
    - Andrew Jackson, PhD, MRCP, Team Member (Consultant Clinical Geneticist, Western General Hospital, Edinburgh, Scotland)




17. SIGNATURES:

I am making a decision whether or not to permit my child to participate in this study. I understand that my child may also have to agree to participate in the study before he/she will be allowed to be in this study. I have read this form, or have had it read to me in a language that I understand. I have been given enough time to make this decision. I have asked questions and received answers about things I did not understand. I willingly give permission for my child to participate in this study. By signing this form, I am not giving up any rights to which I am entitled under law.

I understand that:



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My signature indicates that:

As his or her parent or legally authorized representative, I give my permission for the minor child named below to participate in the research study described in this Parental Permission Form.

I give the researchers and Nemours permission to use and/or disclose my child's individur pa0 Tc