Children's Research Institute
Children's National Health System
111 Michigan Ave, NW
Washington, DC 20010
ChildrensNational.org

August 11, 2016

Dear Patient Family,

You are being contacted because you were/are a participant in the research study entitled New Diagnostic and Therapeutic Approaches in Leukodystrophy, also called the Myelin Disorders Bioregistry Project (MDBP).

I am Dr. Adeline Vanderver, and I am the person in charge of the study, also known as the Principal Investigator (PI). I would like to inform you that I am moving to The Children's Hospital of Philadelphia (CHOP) where I will continue work on this study.

I would like to request your permission to move data and specimens you and/or your child provided when you joined this study (including blood and /or tissue) from the secure laboratory at Children's National to a secure laboratory being set up at CHOP. Moving the data from this study to CHOP will allow me to continue to work to understand leukodystrophies and find causes and treatments for these disorders. The consent form which you signed when you agreed to participate in this study stated that you could "take back" (revoke) your consent at any time by writing to the PI.

If you do not wish for your information and/or samples to be moved, or you no longer wish to be a part of this study, please inform me in writing. You may let me know in one of two different ways:

1. You may email my study team at myelindisorders@childrensnational.org (or if you are receiving this message via email by responding to this email).
2. Alternately, you may write to my team at the following address:

Adeline Vanderver, MD
Division of Neurology
Children's National Health System
111 Michigan Ave NW
Washington DC, 20010

If you are receiving this message via regular mail, you will receive a prepaid envelope in which you may enclose your wishes using the response letter enclosed with this letter.

Please send your response no later than September 8, 2016.

(Letter continues on next page)

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Finally, you may at any point in the future reach out to me to revoke consent and your data will be discarded/destroyed. I can be reached in the future (starting when) at the following address:

Adeline Vanderver, MD
The Children's Hospital of Philadelphia
Lab 514 G Abramson Pediatric Research Center
3615 Civic Center Boulevard
Philadelphia, PA 19104-4318
VANDERVERA@EMAIL.CHOP.EDU

If you have any questions regarding this matter, please feel free to reach out to a member of the MDBP team.

PI: Dr. Adeline Vanderver
Email: avanderv@childrensnational.org

Study Coordinator: Amy Pizzino, MS, CGC
Email: apizzino@childrensnational.org
Phone: 202-476-4975

Sincerely,

Adeline Vanderver, MD

(Response letter on next page)

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Thank you for your participation in the Myelin Disorders Bioregistry Project (MDBP).

Please indicate your wishes below:

- ☐ I agree to having my/my child's data and specimens move to Dr. Vanderver's secure laboratory at CHOP.
- ☐ I do not agree to having my/my child's data and specimens move to Dr. Vanderver's secure laboratory at CHOP but agree to maintaining my/my child's data and specimen's at the secure laboratory at Children's National.
- ☐ I no longer wish to be a part of this study. Please withdraw me/my child from the study.

If participant is UNDER 18 years of age OR has a legal guardian please fill out the section below:

Printed Name of Participant: _____

Printed Name of Parent(s)/Guardian(s): _____

Signature of Parent(s)/Guardian(s): _____Date:_____

Note: If participant is over age 18 and has a legal guardian, please complete the Legally authorized representative (LAR) addendum below.

Signature of Legally Authorized Representative (LAR)

I am authorized to act on behalf of the participant. I have read this information and will receive a copy of this form after it is signed. You agree that we have talked to you about the risks and benefits of the study, and about other choices. You may decide to stop the subject's participation in this study at any time and it will not affect his/her medical care.

By signing this form, you are confirming the following:

1. The study has been explained to the subject (if the subject is able to communicate, even in a limited capacity);
2. The subject understands the study to best of his or her ability; and
3. The subject (if possible) appears to agree to participate.

Printed Name of Legally Authorized Representative:

_____

Signature of Legally Authorized Representative:

_____Date: _____

***If participant is OVER 18 years of age please fill out the section below*:**

Printed Name of Participant: _____

Signature of Participant: _____Date:_____

Note: Participant must be 18 years of age or older