INDIANA UNIVERSITY

AUTHORIZATION FOR THE RELEASE OF HEALTH INFORMATION FOR RESEARCH

You have the right to decide who may review or use your Protected Health Information ("PHI"). The type of PHI that may be used is described below. When you consider taking part in a research study, you must give permission for your PHI to be released from your doctors, clinics, and hospitals to the research team, for the specific purpose of this research study.

This authorization relates to the following study:

School Evaluation and Supports of Children with Pelizaeus-Merzbacher disease 1908479885

TITLE OF THE RESEARCH	**IRB PROTOCOL #**
Michelle Curtin DO	**None**
PRINCIPAL INVESTIGATOR (in charge of Research Team)	**SPONSOR #**
NAME OF RESEARCH PARTICIPANT	**BIRTHDATE**
STREET ADDRESS	**CITY, STATE & ZIP CODE**

What information will be used for research purposes? This form is to allow the release of your health information to be used for the research described above. Your health information includes information that can identify you. For example, it can include your name, address, phone number, birthday and medical record number.

This permission is for health care provided to you found within your child's school testing (psychoeducational assessment), IEP, or shared medical records from the time your child started school to present.

I understand the information listed below will be released and used for this research study:

- Information provided by you
- Medical history / treatment including your child's genetic difference and Pelizaeus-Merzbacher disease diagnosis
- Consultation information from school assessment and Individualized Education Plan (IEP)
- Psychoeducational testing

Specific authorizations: I understand that this release also pertains to records concerning hospitalization or treatment that may include the categories listed below. I have the right to specifically request that records **NOT** be released from my health care providers to the Research Team. However, I understand that if I limit access to any of the records listed below, I **will still** be able to participate in this research study. Check limitations, if any, below:

- ☐ Mental health records
- ☐ Psychotherapy Notes
- ☐ HIV (AIDS)
- ☐ Other: _____
- ☐ Sexually transmitted diseases
- ☐ Alcohol / Substance abuse
- ☐ Sickle Cell Anemia

Who will be allowed to release this information?

I authorize the following persons, groups or organizations to disclose the information described in this Release of Information/Authorization for the above referenced research study:

- Indiana University Health Physicians and Indiana University School of Medicine under the faculty members Dr. Michelle Curtin DO and Dr. Celanie Christensen MD

Who can access your PHI for the study? The people and entities listed above may share my PHI (or the PHI of the individual(s) whom I have the authority to represent), with the following persons or groups for the research study:

- The researchers and research staff conducting the study

- The Institutional Review Boards (IRB) that review the study
- Indiana University
- US or foreign governments or agencies as required by law

Expiration date of the authorization: This authorization is valid until the research ends and required monitoring of the study has been completed.

Efforts will be made to ensure that your PHI will not be shared with other people outside of the research study. However, your PHI may be disclosed to others as required by law and/or to individuals or organizations that oversee the conduct of research studies, and these individuals or organizations may not be held to the same legal privacy standards as are doctors and hospitals. Thus, the Research Team cannot guarantee absolute confidentiality and privacy.

I have the right:

1. To refuse to sign this form. Not signing the form will not affect my regular health care including treatment, payment, or enrollment in a health plan or eligibility for health care benefits. However, not signing the form will prevent me from participating in the research study above.

2. To review and obtain a copy of my personal health information collected during the study. However, it may be important to the success and integrity of the study that persons who participate in the study not be given access until the study is complete. The Principal Investigator has discretion to refuse to grant access to this information if it will affect the integrity of the study data during the course of the study. Therefore, my request for information may be delayed until the study is complete.

3. To cancel this release of information/authorization at any time. If I choose to cancel this release of information/authorization, I must notify the Principal Investigator for this study **in writing** at Dr. Michelle Curtin, DO 1002 Wishard Blvd Suite 3120 Indianapolis, IN 46202. However, even if I cancel this release of information/authorization, the research team, research sponsor(s) and/or the research organizations may still use information about me that was collected as part of the research project between the date I signed the current form and the date I cancel the authorization. This is to protect the quality of the research results. I understand that canceling this authorization may end my participation in this study.

4. To receive a copy of this form.

I have had the opportunity to review and ask questions regarding this release of information/authorization form. By signing this release of information/authorization, I am confirming that it reflects my wishes.

_____
Printed name of Individual/Legal Representative

_____
Signature of Individual/Legal Representative Date

*If signed by a legal representative; state the relationship and identify below the authority to act on behalf of the individual's behalf.

***Individual is:** ☐ a Minor ☐ Incompetent ☐ Disabled ☐ Deceased

***Legal Authority:**

☐ Custodial Parent
☐ Executor of Estate of the Deceased
☐ Authorized Legal Representative
☐ Legal Guardian
☐ Power of Attorney Healthcare
☐ Other: _____