## ***Note to Investigators:*** *Orange italicized text is provided for guidance. Remove all orange, italicized help text and any instructional text prior to submitting this document. This form should be used to obtain parental permission when a minor’s data will be deposited into a repository or data bank.*

**DATA REPOSITORY PARENTAL PERMISSION**

**(NOTE: DO NOT AGREE TO PARTICIPATE UNLESS AN IRB APPROVAL STAMP WITH CURRENT DATES HAS BEEN APPLIED TO THIS DOCUMENT.)**

**Title of research study:** Insert title of research study here with protocol number, if applicable

**Investigator:** Insert name of principal investigator

***Sponsor:*** Include the name of the sponsor or any funding sources

**What is a data repository?**

A data repository holds research data and makes that data available for future use by the broader research community. Many data repositories have restrictions on who can add and access data.

**What is research data?**

Research data is any information the research team gathers about your child for the purposes of conducting this research study.

**What will happen to my child’s research data?**

If you and your child allow us to share your child’s *[choose option 1, 2, or 3, whichever is applicable]*: (1) identifiable (identifiers collected), (2) coded (identifiers collected, and linked to data by code or pseudonym), or (3) anonymous (no identifiers collected)] research data with *[state the name of the data repository]*, other researchers can apply to this data repository to receive a copy of your child’s research data for their own research.

**What are the risks?**

*[Choose option 1, 2, or 3]*

*[Option 1 -* If you and your child allow your child’s identifiable research data to be shared with other researchers, those researchers will know your child’s identity. In addition, researchers who receive a copy of your child’s research data may use your child’s information for purposes you and your child do not intend, including scientific research that you and your child do not agree with or sharing it with others you and your child do not know.*]*

*[Option 2 -* If you and your child allow your child’s coded research data to be shared with other researchers, there are researchers who may attempt to learn your child’s identity without your child’s assent or your permission. In addition, researchers who receive a copy of your child’s research data may use your child’s information for purposes you and your child do not intend, including scientific research that you and your child do not agree with or sharing it with others you and your child do not know.*]*

*[Option 3 -* Researchers who receive a copy of your child’s research data may use your child’s information for purposes you and your child do not intend, including scientific research that you and your child do not agree with or sharing it with others you and your child do not know.*]*

**Can information about my child be destroyed?**

*[Choose option 1, 2, or 3]*

*[Option 1 -* Your child’s identifiable research data in *[name of the data repository]* will be destroyed upon both your and your child’s requests (see below: ‘Do we have to decide now?’). However, *once shared with other researchers*, the shared copy of your child’s research data cannot be destroyed.*]*

*[Option 2 -* Your child’s coded research data in *[name of the data repository]* will be destroyed upon both your and your child’s requests (see below: ‘Do we have to decide now?’). However, *once shared with other researchers*, the shared copy of your child’s research data is cannot be destroyed.*]*

*[Option 3 -* Anonymous research data can never be destroyed.*]*

**What are the benefits?**

You child will likely not benefit directly by allowing their research data to be shared with *[name of the data repository]*.

**Do we have to decide now?**

You and your child do not have to make any decisions right now. Sharing your child’s research data with *[name of the data repository]* is **optional** and not required for your child to participate in this study.

You and your child may ask the research team to share or stop sharing your research data with *[name of the data repository]* at any time by contacting *[name at phone # and email]*. The research team will let you and your child know if it is still possible to share your child’s data with *[name of the data repository]* (for example, sharing may not be possible if the study has ended).

You acknowledge that even if you grant permission for the research team to share your child’s research data, if your child declines, or your child assents and later wants their information destroyed, their decision prevails.

**DATA REPOSITORY DECISION**

Please initial next to your choice:

\_\_\_\_\_\_ I give permission for the research team share my child’s research data with with *[name of the data repository]*.

\_\_\_\_\_\_ I do not want the research team to share my child’s research data with *[name of the data repository]*.

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Child’s Name

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Parent/Guardian or Legally Authorized Representative Signature Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Printed Name of Parent/Guardian or Legally Authorized Representative

­­­­­­­­­­

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Signature of Person Obtaining Permission Date

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Printed Name of Person Obtaining Permission