

# **Consent Form Addendum: Learning About Your Child's Tumor**

## **A. Introduction**

This consent addendum gives new information about the research study in which you agreed to have your child participate in and will ask you to decide whether you would like to receive the results from the sequencing of your child's tumor (somatic) DNA. The procedures noted below are in addition to those which you were informed about in the previous consent form. If you decide to have your child participate in this part of the study, please sign and date the end of this form. You will receive a copy of this form to the email address that you used to register for the project so that you can refer to it while your child is involved in this research study.

If you have any questions, please send an email to [info@osproject.org](mailto:info@osproject.org) or call 651-602-2020 and ask to speak with a member of the study staff about this part of the study.

Results from the sequencing of your child's tumor (somatic) DNA may be able to be shared with you. These results are shared with you to provide you with information about how your child's participation in Count Me In is helping sarcoma researchers, in accordance with your request to receive these results. These results are not meant to replace a clinical genetic test of your child's tumor. These results may not provide all the information your child's doctor needs to make recommendations for their treatment.

## **B. Brief Description of the Project**

The Osteosarcoma Project is part of "Count Me In", a patient-driven movement that enables cancer patients to directly transform cancer research and discovery. People who have been diagnosed with osteosarcoma across the US and Canada have the opportunity to share information about their experience through completing surveys, sharing biological samples (saliva, blood, and/or tumor samples), and copies of their medical records with researchers. Because we are open to participants across the country regardless of where they are treated, this study will allow many more cancer patients to contribute to research than has previously been possible.



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### **C. What are the new procedures involved?**

Because your child has been diagnosed with osteosarcoma and you consented to the study team requesting your child's stored tumor samples, we are asking if you would like to receive what we're able to learn from your child's tumor samples. The information we may be able to share would include a letter and a report about the genetic alterations found in your child's tumor. If you elect to participate, we will contact you through the email associated with your participation when the information we've learned is ready and we will ask that you confirm that you'd like this information before it is shared. If you do not want to receive this information at any time, please inform a study team member by emailing [info@osproject.org](mailto:info@osproject.org).

### **D. Are there any new risks associated with participating in this portion of the research study?**

If you choose to share your child's tumor samples with us and learn more about what we found in sequencing, this process may yield information that is of unclear significance. The risks of learning more about your child's tumor include:

- What we share with you may **not** include all cancer related abnormalities in your tumor specimen. This is because current technologies are not able to find and identify every possible variant that might be related to cancer. You may still have genetic or other variants that are related to your cancer but the tests we performed did not detect them.
- The sequencing may find cancer-related abnormalities in your tumor with unclear significance. You may have heard of some of the genes we find in tumor samples and some people may think they are connected to aspects of the disease, like severity or treatments, even though the evidence is currently unclear. Our goal is to generate data for research to better understand these areas of uncertainty and contribute to changes in knowledge about genes like this.
- It is possible that the information we share with you does not include information about some genes you are expecting to learn about. This is because the information we share will focus on specific research questions in osteosarcoma and does not include a comprehensive list of all possible changes in your tumor.

### **E. Who do I contact if I have questions about the research study?**

If you have questions about the study, please contact the research doctor or study staff listed below by emailing [info@osproject.org](mailto:info@osproject.org) or calling 651-602-2020:



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[www.joincountmein.org](http://www.joincountmein.org)

- Nikhil Wagle, MD
- Katie Janeway, MD
- Corrie Painter, PhD

For questions about your rights as a patient, please contact a representative of the Office for Human Research Studies at (617)-632-3029. This can include questions about your participation in the study, concerns about the study, a research related injury, or if you feel/felt under pressure to enroll in this research study or to continue to participate in this research study. Please keep a copy of this document in case you want to read it again.

**F. Documentation of Consent**

This is what I agree to:

- You can share with me any available results from the sequencing of tumor sample[s] that the study has received.

Yes          No

My signature below indicates:

- I have had enough time to read the consent addendum and think about continuing to participate in this study;
- I have had all of my questions answered to my satisfaction;
- I am willing to have my child continue to participate in this study;
- I have been told that my child's continued participation is voluntary and I can withdraw at any time

Signature:

Date: