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Research Consent Form – Parent or Guardian (Osteosarcoma Project)

Please read through the consent form text below and click “Next” when you are done to move on to the next section. If you have questions about the study or the consent form at any time, please contact us 651-602-2020 or info@osproject.org.

RESEARCH CONSENT FORM (Osteosarcoma Project) – KEY POINTS

1. What is the purpose of this study?
We want to better understand osteosarcoma so that researchers can develop more effective therapies. By partnering directly with patients and their families, we are able to study many more aspects of cancer than would otherwise be possible.

2. What will I have to do if I agree for my child to participate in this study?
After signing a consent form(s), we will ask you to complete a medical release form so that we are able to request your child’s medical records. If you would like to, you can send us a copy of your child’s medical records. If needed, we may contact you to ask if you would be willing to sign additional authorization forms or documents that certain hospitals or centers may require in order to share copies of your child’s medical records with us.

If you choose to share your child’s tumor samples with us, we will ask you to complete a second consent form to tell us whether or not you’d like to hear about what we’re able to learn from your child’s tumor.

You will be asked to complete surveys about your child and their experience with cancer. Additional survey(s) may become available during the course of this research study that you can choose to complete.

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We will ask that you send a sample of your child's saliva to us in a pre-stamped package that we will provide.

If you choose to share a sample of your child's blood with us, we may ask for a sample (or samples) of blood (1 tube, or 2 teaspoons per sample) to be drawn at your child's physician's office, local clinic, or nearby lab facility – we will provide detailed instructions on how to do this.

The project is also partnering with Invitae and Genome Medical in order to sequence and share information on germline DNA ("normal" DNA that is not from your child's tumor) from saliva samples. After we've received your child's saliva sample, we'll reach out to tell you more about this opportunity.

3. Does my child have to participate in this study?
No. Taking part in this study is voluntary. Even if you decide to have your child participate now, you can always change your mind and leave the study at any time.

4. Will it cost me anything to have my child participate in this study?
No.

5. Will you return results to me?
If we are able to successfully sequence your child's tumor sample(s), we can share what we've learned from tumor sequencing with you. When you consent to the study, you'll be able to choose whether or not you'd like to hear about what we're able to learn from your child's tumor.
During the project, you'll be able to decide if you'd like to learn more about your child's germline DNA (or "normal" DNA) through a partnership with Invitae. The resulting information may include details that inform cancer risk for you and your family.

6. Will my child benefit from participating?
While taking part in this study may not improve your child's health, the information we collect will aid in research efforts to provide better cancer treatment and prevention options to future patients and families.

Results from the sequencing of your child's non-tumor (germline) DNA from Invitae may include details that inform cancer risk for your child and your family. You will be offered genetic counselling to help ensure you understand the germline genetic results.

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7. What are the risks of taking part in this research?
If you choose to share a sample of your child's blood, they may experience slight pain and swelling where the blood was drawn.

If you choose to share your child's tumor samples with us and learn more about what we found in sequencing, what the information means for your child's medical care may be unclear.

If you choose to learn more about your child's germline ("normal") DNA, learning about genetic risk for cancer for yourself or relatives may cause worry or fear about the future. You may learn about cancer risks that are unclear, unrelated to your child's current diagnosis or are unexpected based on your child's personal or family history.

There may be a risk that your/your child's information (which includes genetic information and information from your child's medical records or surveys you've completed) could be seen by individuals who do not have permission to view it. However, we have procedures and security measures in place designed to reduce this risk and protect the confidentiality of your information.

A complete description of the risks is provided in the full research consent form.

8. Who will use my child's samples and see my and their information?
Your child's samples and health information will be available to study staff and researchers at Count Me In, the Broad Institute of MIT and Harvard, Boston Children's Hospital, and Dana-Farber Cancer Institute. After removing your child's name and other readily identifiable information, we will share results obtained from your/your child's participation with the greater research community via established public scientific databases.

If you choose to learn more about your child's non-tumor (germline or "normal" DNA), your child's samples and limited health information will be made available to staff at Invitae and Genome Medical. If you choose not to participate in this aspect of the study, your child's information and samples will not be shared with Invitae and Genome Medical.

9. Can my child stop taking part in this research study?

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Yes, you can withdraw from this research study at any time, although any information that has already been shared with researchers cannot be retrieved, and will not be deleted from our databases. Your/your child's information would be removed from future studies.

10. What if I have questions?

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

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FULL RESEARCH CONSENT FORM

Count Me In

A. Introduction

You are being invited to have your child participate in this research study because your child has been diagnosed with osteosarcoma. This study will collect and analyze samples and health information of many patients with osteosarcoma, in order to help doctors and researchers better understand why this disease occurs and develop ways to better treat and prevent them.

Cancers occur when the molecules that control cell growth (such as genes or proteins) become changed or altered. Changes in genes are called “alterations” and can occur in cancer cells or normal tissues. Some alterations that occur in certain types of cancers have already been identified, which has led to the development of drugs that specifically target those alterations. However, the vast majority of tumors from patients have not been studied, which means there is a tremendous amount of information still left to be discovered. A key goal of this research study is to discover more alterations, and to better understand those that have been previously described. We think this could lead to the future development of new or improved ways to treat and prevent cancer.

We may perform different tests or analyses to determine if cells in the samples provided through this study contain any alterations. As an example, we would like to use your child’s DNA to look for alterations in cells using a technology called “sequencing.” Sequencing can be used to read the “letters” of DNA in samples and look for these alterations. Genes are composed of DNA “letters,” which contain the instructions that tell the cells in our bodies how to grow and work. Using gene sequencing as a way to read DNA is one way to identify alterations that may contribute to the behavior of cancer. Some alterations or changes occur only in cancer cells. Other alterations may occur in normal cells as well, including in the genes that may have been passed from parent to child. This research study will examine both normal and tumor samples to look for alterations.

Other than providing 1-2 saliva samples and, if you choose to, blood sample(s) (1 tube or 2 teaspoons per sample), participating in the study involves no new or additional tests or procedures. Tumor samples used for this study will come from stored samples obtained from previous clinical procedures. Study staff will not request samples unless they believe that the material remaining is sufficient for any future clinical needs.

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You are being asked to participate in the study because your child has osteosarcoma. This form explains why this research study is being done, what is involved in participating, the possible risks and benefits of the study, alternatives to participation, and your rights as a participant. The decision to participate is yours. We encourage you to ask questions about the study now or in the future.

B. Why is this research study being done?
We want to understand cancer better so that we can develop more effective therapies. By partnering directly with patients and families, we will be able to study many more aspects of cancer than has previously been possible. In addition, because we are enrolling participants across the country regardless of where they are being treated, this study will allow many more patients to directly contribute to research than might otherwise be feasible.

We will also study how we work with patients and community members to better understand how the scientific community and patients can work together to promote research and generate data.

C. What other options are there?
Taking part in this research study is voluntary – you may choose not to participate. Your decision to not have your child participate will not affect your child's medical care in any way or result in any penalty or loss of benefits.

D. What is involved in the research study?
Provide consent and tell us where your child has been treated: After signing a consent form(s), we will ask you to complete a medical release form so that we are able to request your child's medical records. If you choose to share your child's tumor samples with us, we will ask you to complete a second consent form to tell us whether or not you'd like to hear about what we're able to learn from your child's tumor.

We will take care of obtaining copies of your child's records from the hospitals or centers where your child receives their medical care. If needed, we may contact you to ask if you would be willing to sign additional authorization forms or documents that certain hospitals or centers may require in order to share copies of your child's medical records with us. You may also choose to send your child's medical records directly to us. We may link the information that comes from processing your child's samples with the information from your child's medical records.

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Provide a saliva and/or blood sample: We will ask that your child provides a saliva sample to us in a pre-stamped package that we will provide.

If you choose to share a sample of your child's blood with us, we may ask for a sample (or samples) of blood (1 tube, or 2 teaspoons per sample) to be drawn at your child's physician's office, local clinic, or nearby lab facility – we will provide detailed instructions on how to do this. We may ask your child to provide blood at multiple different time points. We will contact you before sending the blood kit. If you do not want your child to participate in the blood draw at that time, please just inform a study staff member.

Respond to Surveys: You will be asked to complete surveys about your child and their experience with cancer. Additional survey(s) may become available during the course of this research study that you can choose to complete.

You may also be contacted by the team to participate in focus groups, interviews, or additional surveys about your experiences participating in this research. If we decide to contact you, you can choose whether to participate at that time. If you participate, you and your child will be asked to provide feedback about our website, study materials, and our enrollment process. Specifically, we'll ask questions about the Osteosarcoma Project, and what ways we can make it easier for people to learn of this study and consider participation in this research. These interviews may last up to 30-45 minutes and will take place over a video call using a software called Zoom. We will audio-record the interviews so we can remember what you and your child said in your own words. Only the research team will have access to these audio/video recordings. Data will be stored on secure servers at Dana-Farber Cancer Institute. No names, images, or other identifiers will be used in any reports or publications that may result from this research.

Sequencing of samples: If you choose to share your child's tumor samples with us, we may also obtain small amounts of your child's stored tumor samples from hospitals or centers where your child receives their care.

We may study the cells from your child's samples (such as your saliva, tumor samples, and/or blood samples), including the genes found in the cells. No additional procedures will be required. The results will be used to try to develop better ways to treat and prevent cancers.

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Learn more about your child's DNA: The project is also partnering with Invitae and Genome Medical in order to sequence and share information on germline DNA (or DNA that is not from your child's tumor) from saliva samples. After we've received your child's saliva sample, you'll be able to decide if you'd like your child to provide an additional saliva sample to learn more about your child's non-tumor DNA and speak with a genetic counselor to understand these results.

Data sharing: To allow sharing of information with other researchers, the National Institutes of Health (NIH) and other organizations have developed central data (information) banks that analyze, collect, and share the information and results of certain types of genetic studies, for example, the National Institutes of Health/National Cancer Institute data portals such as the Genomic Data Commons and dbGaP and the cBioPortal for Cancer Genomics Some (controlled-access) central data banks may store your child's genetic and medical information and provide the information to qualified researchers to use for further research. Other (open-access) data banks are publicly viewable by anyone with internet access. We will also store your child's genetic and medical information at the Broad Institute of MIT and Harvard and share your child's information with other qualified researchers. Therefore, we are asking your permission to share your child's results with these special data banks and other researchers, and have your information used for future research studies, including studies that have not yet been designed, studies involving diseases other than cancer, and/or studies that may be for commercial purposes (such as the development or approval of new drugs). Your child's information will be sent to central banks and other researchers only with a code number attached. Your/your child's name and other information that could readily identify you or your child will not be shared with central banks or other researchers. We will never sell your or your child's readily identifiable information to anyone under any circumstances.

In some cases, a researcher or study team member may contact you to find out if you / your child would be interested in participating in a different or future research study based on information that may have been found in your child's samples or medical information.

If you signed up for the Osteosarcoma Project before May 2022, information you previously provided (including contact information, survey responses, and medical records) will be shared with this version of the project if you sign this consent form.

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E. How long will my child be in this research study?
We will keep your child's saliva, blood, and tumor samples and medical records indefinitely until this study is finished, unless you inform us that you no longer wish your child to participate. You may do this at any time. More information about how to stop being in the study can be found below in section K: "Can I stop being in the research study and what are my rights?"

Once the study is finished, any leftover saliva and blood samples and copies of your child's medical records will be destroyed. Any tumor samples that we have will be returned to the pathology department at the hospital or other place where your child received treatment.

F. What kind of information could be found in this study and will I be able to see it?
If we are able to successfully sequence your child's tumor sample(s), we will share what we've learned from tumor sequencing with you. When you consent your child to the study, you'll be able to choose whether or not you'd like to hear about what we're able to learn from your child's tumor. The information we are generating for research is unlikely to provide details that would lead to changes in your child's care and treatment plan.

In some cases, we may be able to sequence your child's tumor, but not share what we found with you. This includes (but is not limited to) participants living or treated in New York state and Canada, unsuccessful sequencing, and/or inability for the study to acquire tissue. In these cases if sequencing data is generated, your child's samples will be used to contribute to research, but we cannot share individual results from their tumor samples directly with you.

The project is also partnering with Invitae and Genome Medical in order to sequence and share information on germline DNA (or "normal" DNA) from saliva samples. During the project, you'll be able to decide if you'd like to send an additional sample of your child's saliva to Invitae to learn more about your child's normal DNA. Due to regulatory restrictions, this aspect of the project is unavailable to participants in Canada.

In addition, we will provide general results and major discoveries to all participants. We will do this by regularly updating participants through email newsletters, posts on social media, and/or the website that you used to enroll in this study. We will also publish important discoveries found through these studies in the scientific literature so that the entire research community can work together to better understand cancer. Your child's

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individual data will not be published in a way in which they could be readily identified. Abstracts, which are summaries of the published reports, will be available to you and the general public.

From the interviews with participants, we hope to learn about how we can make it easier for people to find Count Me In, and how we can make it easier to start the process of participating. With this feedback, we will create materials and develop strategies that will help more people participate in this research.

G. What are the benefits of the research study?
Taking part in this research study may not directly benefit your child. By joining this study, you will help us and other researchers understand how to use gene tests to improve the care of patients with cancer in the future. We will provide study participants updates about key research discoveries made possible by your participation.

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 researchers. 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 doctor needs to make recommendations for your child's treatment.

Results from the sequencing of your child's germline ("normal") DNA may include details that inform cancer risk for your child and your family. You will be offered genetic counselling to help ensure you understand the germline genetic results.

H. What are the risks or discomforts of the research study?
<u>Risks/Discomforts from obtaining blood:</u>
If you choose to share a sample of your child's blood, your child may experience slight pain and swelling where the blood is drawn. These complications are rare and should get better within a few days. If they do not, you should contact your child's doctor.

<u>Risks from learning the results of tumor sequencing:</u>
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 tumor include:

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- The sequencing may find no cancer-related abnormalities in your child's tumor specimen. Current technologies are not able to find and identify every possible variant that might be related to cancer. Your child may still have genetic or other variants that are related to their cancer but the tests we performed may not be able to detect them.
- The sequencing may find cancer-related abnormalities in your child's 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 may tell you something about the chances of your child's cancer recurring (coming back) or spreading (becoming metastatic) that may be upsetting.
- It is possible that the testing obtained may not provide all the information intended, or that the results are influenced by sample, sequencing, or analytic quality.

<u>Risks from learning the results of germline ("normal") DNA sequencing:</u>
If you choose to learn more about your child's germline ("normal") DNA, the risks might include the following:

- You may learn about cancer risks that are unrelated to your child's current diagnosis or are unexpected based on your child's personal or family history. Learning about genetic risk for cancer for your child or relatives may cause worry or fear of the future. This worry may be countered by knowing you have an opportunity to address these risks and what to do about them with special follow-up.
- Because your child shares their DNA with family members, some family members may be upset to learn that they may be at risk for cancer or other diseases due to your child's participation in this study.
- It is possible research testing may find no cancer-related abnormalities in your child's normal specimen. In that case, you might have gone through this testing process and not learned anything about your child's risk of cancer. Current technologies are not able to find and identify every possible variant that might be related to cancer. Your child may still have genetic or other variants that are related to their cancer risk but the tests we performed may not be able to detect them.

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Risks to your privacy from data sharing:

There is a risk that your child's information (which may include information from survey responses, your child's medical records, and/or sample testing and analysis) could be seen by people who do not have permission. However, we have procedures and security measures in place designed to minimize this risk and protect the confidentiality of your information. We have tried to minimize this risk by only providing trained study staff members access to where your information is stored. There is a Federal law, known as the Genetic Information Nondiscrimination Act (GINA), which protects your child from genetic discrimination. GINA generally makes it illegal for health insurance companies, group health plans, and most employers to discriminate against your child based on their genetic information. However, this law does not protect your child against genetic discrimination by companies that sell life insurance, disability insurance, or long-term care insurance. If your child already has or has had cancer, any unauthorized disclosure of genetic results is unlikely to change an insurer's view of your child's risk.

Future research studies may include genetic research. Your genes are unique to you. At this time, you cannot be identified through this research, if the samples and specimens are de-identified. There is a risk that you might be reidentified in the future as genetic research progresses.

Your de-identified specimens or genetic data will be placed into one or more publicly-accessible scientific databases. Through such databases, researchers from around the world will have access to de-identified samples or data for future research.

There is a risk that deidentified research data that is shared with outside collaborators may be reidentified. When deidentified data and specimens are shared with outside collaborators agreements limit what the outside collaborators can do with the information to help prevent reidentification.

There is a small but real risk that if your child's samples are used for this research study, they might not be available for clinical care in the future. However, we have attempted to minimize this risk in the following way: the pathologists where your specimens are kept will not release your child's specimen unless they believe that there is enough material remaining for your child's future medical care.

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I. Will I or my child be paid to take part in this research study?
If you/your child complete an interview about your experiences with participating in this research, a $50 gift card will be offered to interview participants. Otherwise, there is no financial compensation for participation in this study.

J. What are the costs to take part in this research study?
There are no costs to you or your child to take part in this study.

K. Can my child stop being in the research study and what are my child's rights?
Your child can stop being in the research study at any time. We will not be able to withdraw all the information that already has been used for research. If you tell us that you want your child to stop being in the study, we will return any remaining tumor samples from where we obtained them, and destroy any remaining samples we have. We will not perform any additional tests on the samples. Additionally, we will not collect any additional medical records and we will destroy the copies of the medical records we already have. However, we will keep the results from the tests we did before your child stopped being in the study. We will also keep the information we learned from reviewing your child's medical records before they stopped being in the study. We will not be able to take back the information that already has been used or shared with other researchers, central data banks, or that has been used to carry out related activities such as oversight, or that is needed to ensure quality of the study.

To withdraw your permission, you must do so in writing by contacting the researcher listed below in section N: "Whom do I contact if I have questions about the research study?" If you choose for your child to not participate, or if they are not eligible to participate, or if you withdraw your child from this research study, this will not affect your child's present or future care and will not cause any penalty or loss of benefits to which you/your child are otherwise entitled.

L. What happens if my child is injured or sick because they took part in this research study?
There is little risk that your child will become injured or sick by taking part in this study. There are no plans for this project to pay you/your child or give you other compensation for any injury. You and your child do not give up your legal rights by signing this form. If you think your child has been injured as a result of taking part in this research study, please tell the person in charge of this research study as soon as possible. The research doctor's contact information is listed in this consent form.

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M. How will this study protect patient confidentiality?
We will take rigorous measures to protect the confidentiality and security of all your and your child's information, but we are unable to guarantee complete confidentiality. Information shared with the research team through email, or information accessible from a link in an email, is only protected by the security measures in place for your email account. Information from your child's medical records and genomic, histologic, and/or molecular tests will be protected in a HIPAA compliant database. HIPAA is a U.S. federal law that established national standards to protect sensitive health information from being disclosed without a patient's consent or knowledge.

Your child's name and other information that could be used to readily identify them will be removed from your child's samples, and replaced by a randomized code. If we send your child's samples to other researchers for testing, the samples will be identified using only this code.

We will store all of your child's identifiable information related to the study (including your child's medical records) in locked file cabinets and in password-protected computer files or secure databases at the Broad Institute and we will limit access to such files. We may share your child's identifiable information or coded information, as necessary, with regulatory or oversight authorities (such as the federal Office for Human Research Protections), ethics committees reviewing the conduct of the study, or as otherwise required by law.
When we send information to central data banks or other researchers, it will not contain your child's name or other information that could be used to readily identify your child.

The results of this research study may be published in research papers or included in presentations that will become part of the scientific literature. Your child will not be identified in publications or presentations.

N. Whom 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 or calling 651-602-2020:
• Nikhil Wagle, MD
• Katie Janeway, MD
• Corrie Painter, PhD

For questions about your child's rights as a patient, please contact a representative of the Office for Human Research Studies at (617)-632-3029. This can include questions

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about your child's participation in the study, concerns about the study, a research related injury, or if you feel/felt under pressure to enroll your child 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.

O. Authorization to use your child's health information for research purposes

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that requires Dana-Farber/Harvard Cancer Center (DF/HCC) and its affiliated research doctors, health care providers, and physician network to protect the privacy of information that identifies your child and relates to your child's past, present, and future physical and mental health conditions ("protected health information"). If you enroll your child in this research study, your child's "protected health information" will be used and shared with others as explained below.

Because information about your child and their health is personal and private, it generally cannot be used in this research study without your written authorization. Federal law requires that your child's health care providers and healthcare institutions (hospitals, clinics, doctor's offices) protect the privacy of information that identifies your child and relates to their past, present, and future physical and mental health conditions.

If you sign this form, it will provide your child's health care providers and healthcare institutions the authorization to disclose your child's protected health information to the Broad Institute for use in this research study. The form is intended to inform you about how your child's health information will be used or disclosed in the study. Your child's information will only be used in accordance with this authorization form and the informed consent form and as required or allowed by law. Your child's treatment, payment, enrollment or eligibility for benefits does not depend on whether or not you sign this Authorization. Any information disclosed because of this Authorization may be re-disclosed by the recipient of the information and is no longer protected by federal or state privacy laws. Please read it carefully before signing it.

1. What personal information about my child will be used or shared with others during this research?

· Health information created from study-related surveys
· Your child's medical records
· Your child's saliva sample

If elected (at the end of this form):

· Your child's blood sample(s)

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· Your child's tumor samples relevant to this research study and related records

2. Why will protected information about my child be used or shared with others? The main reasons include the following:
· To conduct and oversee the research described earlier in this form;
· To ensure the research meets legal, institutional, and accreditation requirements;
· To conduct public health activities (including reporting of adverse events or situations where you or others may be at risk of harm);
· To better understand the diseases being studied and to improve the design of future studies

3. Who will use or share protected health information about my child?
The Broad Institute and its researchers and affiliated research staff will use and/or share your child's personal health information in connection with this research study.

4. With whom outside of the Broad Institute may my child's personal health information be shared?
While all reasonable efforts will be made to protect the confidentiality of your protected health information, it may also be shared with the following entities:
· Federal and state agencies (for example, the Department of Health and Human Services, the Food and Drug Administration, the National Institutes of Health, and/or the Office for Human Research Protections), or other domestic or foreign government bodies if required by law and/or necessary for oversight purposes.
· Outside individuals or entities that have a need to access this information to perform functions relating to the conduct of this research such as data storage companies and pathology labs.

5. For how long will protected health information about my child be used or shared with others?
There is no scheduled date at which your child's protected health information that is being used or shared for this research will be destroyed, because research is an ongoing process.

6. Statement of privacy rights:
· You have the right to withdraw your permission for the doctors and researchers to use or share your child's protected health information. We will not be able to withdraw all the information that already has been used or shared with others to carry out related activities such as oversight, or that is needed to ensure quality of the study. To withdraw

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your permission, you must do so in writing by contacting the researcher listed above in the section: “Whom do I contact if I have questions about the research study?”
· You have the right to request access to your child’s personal health information that is used or shared during this research and that is related to your child’s treatment or payment for their treatment. To request this information, please contact your child’s doctor who will request this information from the study directors.

P. Participation Information
We may ask you for information about contacting your child’s physicians and the hospitals that you were treated at for your cancer. We will not disclose details about the results of your child’s participation in this study with any of the individuals that we contact, but rather ask them to provide us with your child’s medical history and (if you have agreed) your child’s tumor samples.

Q. Documentation of Consent
This is what I agree to:

Please Check “Yes” or “No” for each point below:

· You can work with me to arrange sample(s) of my child’s blood to be drawn at my child’s physician’s office, local clinic, or nearby lab facility. You can perform (or work with others to perform) genomic and/or molecular tests on blood sample(s), and store the sample(s) until this research study is complete.

☐ Yes ☐ No

You can request my child’s stored tumor samples (e.g. tumor biopsies, surgical specimens, bone marrow samples, etc) from my child’s physicians and the hospitals and other places where my child received care, perform (or work with others to perform) genomic, histological, and/or molecular tests on the samples, and store the samples until this research study is complete.

☐ Yes ☐ No

In addition, I agree to all of the following:

- You can perform (or work with others to perform) genomic and/or molecular tests on the sample(s) of my child’s saliva that I will send you and store the sample(s) until this research study is complete.
- You can request my child’s medical records from their physicians and the hospitals and other places where my child received and/or continue to receive

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treatment and link results of any tests you perform on my child's saliva and blood and tumor samples (if I have chosen to share them with you) with my child's medical record information.

- You can store the answers that I provide in study surveys until this research study is complete. You can contact me to notify me as additional survey(s) become available during the course of this research study that I can choose to complete.
- You can study and share the results of the genomic, histologic, and/or molecular tests, survey responses, and my medical information with established public databases (e.g., NIH/NCI data portals, cBioPortal for Cancer Genomics, Tumor Portal, The Exome Aggregation Consortium/Genome Aggregation Database) and with other qualified researchers in a manner that does not include my child's name, or any other information that could be used to readily identify me or my child, to be used by other qualified researchers to perform future research studies, including studies that have not yet been designed, studies for diseases other than cancer, and studies that may be for commercial purposes.
- You can share my child's information and records with this study if I signed my child up to participate in the Osteosarcoma Project before May 2022.
- You can use the results of studying my child's biological samples and my child's medical information for future research studies, including studies that have not yet been designed, studies for diseases other than cancer, and/or studies that may be for commercial purposes.
- You can contact me in the future for reasons related to this research study, such as to ask if I would be willing to sign any additional documents that my child's hospital(s) may require in order to share their medical records, and/or to verify information about saliva or blood samples my child provides.
- You can contact me in the future to participate in additional surveys, individual interviews, or focus groups about my/my child's experience in this study.
- You can record and store transcripts of interviews or focus groups that I or my child participate in about my/their experience of the study.

My full name below indicates:
I have had enough time to read the consent and think about agreeing to have my child participate in this study;
I have had all of my questions answered to my satisfaction;
I am willing to have my child participate in this research study
I have been told that my child's participation is voluntary and if I decide not to have my child participate it will have no impact on my child's medical care;

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I have been told that if I decide to have my child participate now, I can decide to withdraw my child from the study at any time.
I acknowledge that a copy of the signed consent form will be sent to my email address

Your child's First **Name:**

Your child's Last Name:

Your child's Date of Birth (mm/dd/yyyy):

Your First Name:

Your Last Name:

Relationship to child (Parent/Guardian)

Date:

Your Signature (Full Name)**:**

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Research Assent Form – Child/Adolescent Assent Form (Osteosarcoma Project)

The form below will tell you more about the research study and how to be part of the osteosarcoma project. If you have questions about the study or the consent form at any time, please have your parent contact us at 651-602-2020 or info@osproject.org.

RESEARCH ASSENT FORM (Osteosarcoma Project)

We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about osteosarcoma by having osteosarcoma patients share their medical records, saliva and/or tissue or blood samples with researchers. You are being asked to join the study because you had or have osteosarcoma.

If you agree to join this study, your parent will be asked share information about where you were treated and you will be asked to provide a saliva sample with a kit sent by the project team. You can also choose to share a blood sample, if you want. After that, the project team will take care of the rest. They will request medical records and get tumor samples and process the blood and saliva kits. All of this information will help researchers better understand osteosarcoma.

If you choose to share a blood sample, there are small risks from getting a sample of blood. You may have pain and swelling at the site of the blood draw.

Joining this research study may not improve your health, but we may learn something that will help others with osteosarcoma one day.

You do not have to join this study. It is up to you. You can say okay now and change your mind later. All you have to do is tell your parent that you want to stop. No one will be mad at you if you don't want to be in the study or if you join the study and change your mind later and stop.

If you have any questions about this study, please have your parent contact the project team at 651-602-2020 or info@osproject.org

If you sign your name below, it means that you agree to take part in this research study.

Child/Adolescent Assent

Name:

Date: