|  |  |  |  |
| --- | --- | --- | --- |
| Segment ID | Segment status | Source segment | Target segment |
| 1bcf0cde2-221c-4fc3-9f62-3f9420855a4c | Not Translated (0%) | <2>TBANK:</2> |  |
| 220f71d1d-ef93-49e5-b793-0ee18915604b | Not Translated (0%) | <5>PROTOCOL FOR COLLECTING, BANKING AND DISTRIBUTING HUMAN TISSUE SAMPLES</5> |  |
| 3a151fdf2-5985-48c1-8c57-eff37e3fd5fc | Not Translated (0%) | <6/><7/>NOTE:<8/><9/> |  |
| 43747889e-6fab-4f65-9766-fb93bb0c61a6 | Not Translated (0%) | <12>When we say “you” in this consent, we mean “you or your child.”</12> |  |
| 5a181a44f-12dc-4de8-a4e5-6f68de2d9e08 | Not Translated (0%) | <15>What is the purpose of the biorepository?</15> |  |
| 6fed24272-c417-4823-84f3-9908e38d5d55 | Not Translated (0%) | You are being asked to donate your tissue samples and health information to the St. Jude Biorepository because you are a patient, parent, relative or legal guardian of a patient, or a healthy volunteer. |  |
| 7956f2575-711a-479a-aa93-e2cca2620c7c | Not Translated (0%) | Once you understand the purpose of the biorepository, risks and benefits of donating samples and health information, and you agree to participate, you will be asked to sign this consent form and we will give you a copy. |  |
| 88a43d116-9ea2-49fc-a951-be12678b311e | Not Translated (0%) | A biorepository is a laboratory that collects, stores and provides human tissue samples and health information for current and future research. |  |
| 91a3013d2-8a93-4856-b0ea-9051451ef104 | Not Translated (0%) | Gathering and storing samples and health information in a biorepository provides important resources for researchers so they may learn more about diseases and conditions and develop new diagnostic tests, and new treatments for many kinds of diseases. |  |
| 10b3088a41-8199-4a4d-98b1-6ac3401e6417 | Not Translated (0%) | Samples and information that are banked are used for a wide range of research including the study of genetic diseases. |  |
| 11a2cae191-4846-450a-9afb-e2333f6207c8 | Not Translated (0%) | Your specimens may undergo whole genome sequencing. |  |
| 1243765063-efb1-4cb3-8911-cbfe12392a28 | Not Translated (0%) | A genome is made of DNA and contains the complete set of genetic instructions. |  |
| 13e53704d4-909a-4eb7-9241-a0cc6f6ecccb | Not Translated (0%) | Genetic diseases may be inherited, for example, sickle cell anemia, cystic fibrosis and epilepsy. |  |
| 14aed2e705-242c-49af-9540-feea3e7feba8 | Not Translated (0%) | Cancer is commonly a genetic disease, and may be caused by inherited genetic changes, and genetic changes that occur in cells after birth. |  |
| 156aa49c68-ed35-47e6-8363-5924dd749414 | Not Translated (0%) | Samples may also be used to create “cell lines”. |  |
| 162a533d88-86f7-46b4-a70e-7b3cabf171fa | Not Translated (0%) | Cell lines are created by growing cells from samples into more cells either in the laboratory, or in other species such as mice. |  |
| 179b01126f-9309-40f5-8625-1dd756b5a40b | Not Translated (0%) | Human samples grown in other species are called “xenografts.” |  |
| 180127b3f2-a2f3-4d00-b1d9-7d904bf8d530 | Not Translated (0%) | Cell lines and xenografts made from donated samples will also be stored in the St. Jude Biorepository and research laboratories and used for research. |  |
| 1919619d19-d68c-4b43-9d9e-1ce550da6015 | Not Translated (0%) | It is important that you know the following: |  |
| 202afacc2b-735c-4cbb-869a-7230c7ae095c | Not Translated (0%) | The choice to donate your samples and health information is up to you and will not affect your treatment. |  |
| 21b9adfd14-af0a-4211-ad56-0d7ffad78d61 | Not Translated (0%) | You may decline to donate samples for research. |  |
| 220e0c31ad-425a-4d37-a1be-6154cb21dc26 | Not Translated (0%) | You may stop us from using your samples and or health information for research at any time. |  |
| 23739b68b5-8c60-46a6-9f5a-56d8c90de47c | Not Translated (0%) | You can request that your tissue samples be removed from the Biorepository and destroyed. |  |
| 2479a34a60-dacd-4d36-bd74-8d7b2e2a2d79 | Not Translated (0%) | However, we cannot retrieve samples and information that has already been given to researchers or used in research studies. |  |
| 25c5b077e6-f24c-4009-a06a-444c44c32199 | Not Translated (0%) | <18>If you have questions or concerns before or after agreeing to donate to the Biorepository, you can contact Dr. Charles Mullighan, the Medical Director of the Biorepository (901-595-3387 or </18>charles.mullighan@stjude.org) or Matthew Lear, the Technical Director (901-595-2528 or matthew.lear@stjude.org). |  |
| 26d9946e8e-0b0b-40d4-a7db-a2fb51024750 | Not Translated (0%) | NIH/NCI has developed a useful brochure (in English and Spanish) about tissue research, which can be found at: <25><20/><21/>http://www.cancer.gov/clinicaltrials/resources/providingtissue/<22/><23/></25> |  |
| 278f367646-efb6-418e-b9e4-c11f2fb07b61 | Not Translated (0%) | <26/>I<27/>f you have questions about your rights as a research participant, you can contact the St. Jude Institutional Review Board at 901-595-4357 or the Research Participant Advocate at 901-595-4644. |  |
| 287f8663bb-e60b-4265-ac1e-d3aa2d3b3a1b | Not Translated (0%) | (Toll-free 1-866-583-3472).<28/> |  |
| 292a7fedf9-550e-4bf3-9ce6-e0bc4ef40b81 | Not Translated (0%) | <31>What will be done?</31> |  |
| 302b18f745-d28a-40ec-82f0-10c0c1a5542d | Not Translated (0%) | Left over material from your biopsy, surgery, spinal tap, blood draw or other medical care will be collected at any time now or in the future and stored in the St. Jude Biorepository. |  |
| 3121e6513c-789d-4edb-8bcf-3c8bc5c16a45 | Not Translated (0%) | Extra amounts of blood or other body fluid, or tissue samples may also be collected during routine medical procedures. |  |
| 328e9b3eef-13fe-464f-869d-e592ed7a260c | Not Translated (0%) | In these cases, about 2-6 teaspoons of extra blood or bone marrow or an extra ½ teaspoon of cerebrospinal fluid (fluid surrounding brain and spinal cord) will be drawn. |  |
| 337bb3789f-bb7c-4248-886a-fba77620e90c | Not Translated (0%) | For individuals who are not patients, we may collect a blood sample or a sample from your cheek using a swab. |  |
| 349d588e8d-9725-4672-a175-296b663a85a7 | Not Translated (0%) | We may collect about 2 tablespoons of blood, depending on your age and weight. |  |
| 353cac1ae4-3448-459b-9210-71af92bb177f | Not Translated (0%) | We will collect basic health information from you and your medical records. |  |
| 366fe3586d-439a-4b03-b3bc-1c42a2f78d29 | Not Translated (0%) | More detailed information will be collected when needed for research. |  |
| 37d5123c58-5970-415f-b13b-b4bc4bb0f460 | Not Translated (0%) | Examples of information that will be used for research include your medical history and physical exams, health status, results of laboratory tests, medical procedures, x-rays, scans, treatments and medications. |  |
| 3800218a13-5aa1-4208-9906-6badc4172e56 | Not Translated (0%) | <34>How will samples and health information be stored?</34> |  |
| 392451a4ce-6a05-4b48-a5ca-27791df6fdd7 | Not Translated (0%) | Your donated samples and basic health information will be stored in the St. Jude Biorepository until the samples are used up or until you ask for them to be removed from the Biorepository. |  |
| 4018411f08-9c4d-42b8-b4c7-3cb8f52ddbdd | Not Translated (0%) | Health information will be used indefinitely, unless you ask us to stop using it for research. |  |
| 4129999e4c-d915-4de8-88b9-3c2d12ea3b98 | Not Translated (0%) | Your identity will be removed from the samples and they will be labeled with a unique code. |  |
| 42bfcf745f-081b-41f3-99ab-2416ee062c1e | Not Translated (0%) | The Biorepository will maintain a link between the code and your identity. |  |
| 43df662ef4-72d7-4399-9016-b80103b9ab41 | Not Translated (0%) | Codes and any private health information will be kept in a password protected database that is protected by a firewall. |  |
| 449cc45141-a9cf-4d3e-88c3-f2f32d1c68dc | Not Translated (0%) | Only authorized Biorepository staff will have access to the database. |  |
| 4511193213-6762-4338-9cdc-ee2c1601cf6a | Not Translated (0%) | Samples will be kept in locked freezers and only authorized Biorepository staff will have access to the freezers. |  |
| 466cfedd56-589c-45f9-8a9d-1d37748872e8 | Not Translated (0%) | <37>How will samples and health information be shared?</37> |  |
| 477e3e7c28-a35f-404f-b6b8-b7a27fb4ac15 | Not Translated (0%) | Requests to use your samples and health information for research are reviewed and approved by a committee of scientists who review the research to make sure it is good science. |  |
| 48447b69fb-b233-4e15-af88-a28307ba11ef | Not Translated (0%) | Most research will not require knowing who you are. |  |
| 492632da50-eca6-4a43-b8c8-3fd5fdbc5aa5 | Not Translated (0%) | However, there are cases that your identity is needed to conduct research. |  |
| 50290b3e8b-459b-4f9b-93d1-3b833441116f | Not Translated (0%) | When your identity is necessary, researchers must also obtain approval from the St. Jude Institutional Review Board (IRB). |  |
| 51d0255718-7c47-4a6f-bc36-b9cf09d15a82 | Not Translated (0%) | The IRB is a regulatory board that reviews, monitors, and approves all research studies involving humans. |  |
| 52b94be001-a638-416a-b90b-481967a1514f | Not Translated (0%) | The IRB follows state and federal laws as well as ethical codes to make sure your rights and welfare are protected. |  |
| 53a5de63e5-7253-4c42-9053-0e699e7e6d99 | Not Translated (0%) | <38/>Research data and samples are shared with other researchers at St. Jude and elsewhere. |  |
| 54bb44c26b-6e0b-4926-bbda-ea459cc93c0d | Not Translated (0%) | This sharing allows for more research and important research findings. |  |
| 55ef367918-4a6f-4725-9f9b-dbd20d06db00 | Not Translated (0%) | <39/><40/>You will not be notified every time your samples and information are used for research. |  |
| 569efc17fc-384c-4593-9d80-11c396a28019 | Not Translated (0%) | If researchers require additional information or testing from you, you will first be contacted by Biorepository staff or your primary physician to ask if a researcher can contact you. |  |
| 57a37c4a22-4ee1-45ba-8054-7b64389b09cc | Not Translated (0%) | If you agree, the Biorepository will provide the researcher your contact information. |  |
| 58cf58a95b-51a6-44b3-930d-ea87f1f4c88a | Not Translated (0%) | If you do not agree, you will not be contacted by the researcher.<41/> |  |
| 59d8f90bef-ec51-4a1e-bb73-a3207348a192 | Not Translated (0%) | Research data obtained from tumor and normal specimens, such as genetic data, are often shared with the research community using various databases, including those maintained by St. Jude, the federal government, and international collaborative databases. |  |
| 60513f09dd-5279-4b15-8bb8-febcccaf082f | Not Translated (0%) | This is to advance scientific discovery, and to satisfy requirements of organizations that fund research, and journals that publish the results of research. |  |
| 614d486438-d8dd-4d32-bcfc-ed5f95c67eb7 | Not Translated (0%) | There are two types of databases used for sharing research data. |  |
| 623b08c031-e960-4ad2-adc5-682d15a26b1d | Not Translated (0%) | One is a public, unrestricted access database and the other is a controlled access database. |  |
| 634b26c462-987c-447f-85c8-5067e22e2b1f | Not Translated (0%) | Each is described below. |  |
| 644a91d7cc-06d7-489b-9839-1fd83b412595 | Not Translated (0%) | <42/><43/><44/>Unrestricted access databases:<45/><46/> |  |
| 6594f2c709-68a9-43a7-93c7-2e7c9f4acb35 | Not Translated (0%) | <47/><48/>The information from research studies using your samples, genetic information and health information may be freely available in a public, unrestricted database that anyone can use. |  |
| 6671e35c80-f98e-4627-b86e-c16dc8395dde | Not Translated (0%) | A public database could include information on hundreds of thousands of genetic variations in your DNA code, as well as your ethnic group and sex. |  |
| 676cf121fb-c55d-474b-a268-cf99a328054a | Not Translated (0%) | S<49/><50/>ummary-level information about all participants included in a dataset, including you, but not genetic data for each individual, may be shared. |  |
| 6811ac418b-83fc-466c-b634-0587c33ee78f | Not Translated (0%) | Some examples of information that may be shared includes how different genes are associated with different traits or diseases across the many participants in the dataset, or how often certain gene changes are seen across participants from many studies. |  |
| 69235cbfd0-43af-412d-b329-a863a049be61 | Not Translated (0%) | However, the risk of anyone identifying you with this information is very low. |  |
| 705b54496e-eb51-47a3-8bf4-5ff68a6b30e6 | Not Translated (0%) | <51/><54>This public information will not be labeled with your name or other information that could be used to easily identify you.</54> |  |
| 71337e763c-a8cb-483c-a283-f347f437f7ea | Not Translated (0%) | <62><56/><57/>Controlled access databases<58/><59/><60/>:</62> |  |
| 72af901b24-0299-40c1-92cc-359c4d244318 | Not Translated (0%) | Your individual genomic data and health information may be put in a controlled-access database. |  |
| 73bae591d3-c29b-45c2-ad28-aa76c4508ffe | Not Translated (0%) | This means that only researchers who apply for and get permission to use the information for a specific research project will be able to access the information. |  |
| 74a8be84e1-664f-4bc4-9e80-6981c50c162a | Not Translated (0%) | Your genomic data and health information will not be labeled with your name or other information that could be used to identify you. |  |
| 758428f3de-f19d-41a9-b3d8-72fb1e52d92b | Not Translated (0%) | Researchers approved to access information in the database must agree not to attempt to identify you. |  |
| 76b7f23e1a-3f60-4f42-b60f-3aa54d3d6e07 | Not Translated (0%) | Examples are the St Jude Cloud which is run by St Jude, the database of Genotypes and Phenotypes which run by the Federal Government and the European Genome-Phenome archive. |  |
| 778d4edb06-0837-411b-934d-fdc870eec60d | Not Translated (0%) | These are databases available to researchers to use genomic information from tumor and non-tumor samples to study genetic changes in pediatric diseases.<63/> |  |
| 7862f887b6-b7f7-4729-9495-7be609311be0 | Not Translated (0%) | <66>Will I be given research results or findings?</66> |  |
| 795a2f4b4f-ddcb-4854-950e-21f041d51816 | Not Translated (0%) | You will not be given individual research results. |  |
| 80a5e0808d-0efb-4fb7-8cde-880fc9b705dd | Not Translated (0%) | Most researchers will not know your identity. |  |
| 81d029877a-e3f0-46bf-be77-c006dcfd38eb | Not Translated (0%) | By law, research results cannot be reported to you or your physicians. |  |
| 82b53046bd-1273-4f2f-9655-a85c739831b0 | Not Translated (0%) | However, we may contact you to provide counseling and offer clinical testing if researchers discover something that could affect you or your family’s health. |  |
| 83e4555b25-9ec6-484c-99dc-046900938d33 | Not Translated (0%) | You can refuse this information unless the information concerns a minor child, is related to a disease that is serious, and could possibly be prevented or treated before the child turns |  |
| 842e8218a4-f40d-4031-9034-deb66241ef3a | Not Translated (0%) | 18. |  |
| 852c39673d-6bc7-4d11-8632-bffa77483082 | Not Translated (0%) | If you are not contacted, this does not mean that you do not have any genetic variants (changes) that might be related to a disease or condition. |  |
| 866f2caa9c-a376-4d5c-b179-0d1c1877f5d9 | Not Translated (0%) | <69>Is there a risk of harm associated with donating samples and health information for research?</69> |  |
| 87190511e5-2379-4315-a29d-f6b4ad81e2f5 | Not Translated (0%) | Donating samples poses little or no physical risk beyond the risks of the procedure itself. |  |
| 88e4f5cd1f-5b18-466b-9a33-ee81f1d8d3dd | Not Translated (0%) | The risks of a blood draw include brief stinging pain, bruising, and slight bleeding at the needle site. |  |
| 89ace39b63-a984-4510-a27a-c6cb64d79b3f | Not Translated (0%) | Rarely, the needle stick site may become infected. |  |
| 9003b7178a-f21b-40a9-a1d4-c73f74080777 | Not Translated (0%) | Some people may feel faint. |  |
| 91496da5b3-287c-4dd7-8eba-de294c5ea6df | Not Translated (0%) | The risks of biopsy or other procedures, such as lumbar puncture (spinal tap) will be discussed separately with you. |  |
| 92aa63f3f6-db9f-4e8d-885c-5be2409380a2 | Not Translated (0%) | The primary risk from donating samples and health information for research is the accidental release of or unauthorized access to, your private information. |  |
| 93b68dac96-fc6c-46af-9e65-8663b9f51b61 | Not Translated (0%) | This could result in embarrassment, loss of employment, discrimination or criminal charges. |  |
| 94494700bf-6e6b-4cfe-a00e-47e2d9d6ca7f | Not Translated (0%) | In the unlikely case that your genetic information is taken and linked back to you, it could be used in ways that cause you or your family distress. |  |
| 951ca16877-dae3-4344-81de-5ecef66eabab | Not Translated (0%) | Also, some genetic results can help predict future health problems that may affect you and your relatives. |  |
| 96454d03f6-abd6-4eea-9634-ddad09550656 | Not Translated (0%) | This may be information that if told to you, could cause you and your family distress or psychological harm. |  |
| 97586fc026-97d0-4725-bf15-01144991ae4a | Not Translated (0%) | <72>Are there benefits from donating samples and information to the Biorepository?</72> |  |
| 984c7410de-e9ef-47ab-b1c7-50dcf524bb30 | Not Translated (0%) | Donating samples to the St. Jude Biorepository will likely not benefit you directly. |  |
| 999ecc41a6-dd1b-4171-ae7e-b596599e36b0 | Not Translated (0%) | What we learn from current and future research studies using donated samples and information may help people in the future. |  |
| 10058a5a862-4366-48ee-888f-fc7c3cf18cdc | Not Translated (0%) | <75>How will privacy and confidentiality be protected?</75> |  |
| 101448cc8f2-922b-40c1-a67e-fef3c35b5fd9 | Not Translated (0%) | When you first registered at St. Jude, you received a copy of the St. Jude Notice of Privacy Practices. |  |
| 102c6e47f63-4d45-4d0d-8b76-c71dbb2f852e | Not Translated (0%) | It tells how your PHI (protected health information) may be used or given to someone outside the hospital. |  |
| 103651fa2a8-7427-4251-b51a-0e49f90155ee | Not Translated (0%) | You have the right to read the Notice of Privacy Practices before you sign this form. |  |
| 104de135543-4469-46b4-8ebf-319990f6055b | Not Translated (0%) | It may have changed since you first registered at St. Jude. |  |
| 105f4a78a3a-caae-44db-93c2-df5b57900482 | Not Translated (0%) | You can find it at the bottom of every page on the St. Jude Internet website: <82><77/><78/>www.stjude.org<79/><80/></82>. |  |
| 10679ac939e-0fb0-42b3-b844-1165bc0bbfc6 | Not Translated (0%) | http://www.stjude.org/ |  |
| 107cdb46be6-4375-4728-b130-7515f566e75c | Not Translated (0%) | There is a Federal law called the Genetic Information Nondiscrimination Act (GINA). |  |
| 108a19c6ae0-0983-4195-97e2-ac07346824f9 | Not Translated (0%) | In general, this law makes it illegal for health insurance companies, group health plans, and most employers to discriminate against you based on your genetic information. |  |
| 10976182941-1432-4fb8-8755-64dd0510faa2 | Not Translated (0%) | However, it does not protect you against discrimination by companies that sell life insurance, disability insurance, or long-term care insurance. |  |
| 110de3beac4-8110-4ac1-a875-77cb8cfee026 | Not Translated (0%) | The Biorepository has received a Certificate of Confidentiality from the federal government. |  |
| 111d65409a2-b01d-4959-85d1-eae8dec5303f | Not Translated (0%) | The Certificate of Confidentiality protects release of your personal medical information or samples even if a court orders St. Jude to release them. |  |
| 112f3c7a472-96a4-4063-8478-2045ec338c05 | Not Translated (0%) | You can still give permission for personal information to be released. |  |
| 113e16b305a-756e-4a26-b0b6-d8937d2603ca | Not Translated (0%) | The Certificate of Confidentiality does not protect release of information in certain circumstances. |  |
| 114ca269383-694b-4684-a4f5-d12b6958bca5 | Not Translated (0%) | These include clinical or research data that are placed in the medical record for the purposes of clinical research and clinical care. |  |
| 1157dac1106-901e-441b-9065-a087d9423e4a | Not Translated (0%) | In addition, researchers and study staff are required by law to report suspected child abuse, and neglect, or harm to self or others. |  |
| 11688d0d5a9-c77e-4f32-8498-bb6ae63f6eb1 | Not Translated (0%) | Tennessee state law requires researchers to report every case of certain contagious diseases they find. |  |
| 1179e9bde0b-e9fc-4d75-985d-cfa9438011d1 | Not Translated (0%) | These diseases all spread easily between people, and if you are found to have one of the diseases named in the law, you will be told, so you can be given treatment to help control the spread of the infection. |  |
| 11887c4dbfc-caa1-4b58-a51b-163c7eed174f | Not Translated (0%) | Results of future research may be published or discussed in conferences. |  |
| 1192ca82785-46a3-4f17-b920-b361ce2b1667 | Not Translated (0%) | Your name, medical record number, and similar identifying information will not be included unless you agree. |  |
| 12063796efb-c5de-4af8-b45f-9fdc2ea61706 | Not Translated (0%) | The Biorepository has many years of experience in preventing unauthorized access to information. |  |
| 1210668e617-9840-4e0a-a052-a658a167ebd5 | Not Translated (0%) | Your privacy and the confidentiality of your information are very important to us and we will take significant efforts to protect them. |  |
| 122b2bfd466-c735-47d8-8c01-560ce8081a78 | Not Translated (0%) | Additionally, wherever possible, the information will be released without information that may personally identify you, such as your name, address and date of birth. |  |
| 12366d9a383-4180-4649-a7e6-833b2326d48e | Not Translated (0%) | Personally identifiable information is rarely released for research purposes, and must be required in order for scientifically justified research to be performed, and must have the approval of the St Jude Institutional Review Board. |  |
| 124b34069e1-fa5b-419d-992a-8fb6ac1b8f2c | Not Translated (0%) | <85>What are the costs and will I be paid for my donation?</85> |  |
| 1258c893c48-6a7f-4a5c-9a68-06e84b9e2c24 | Not Translated (0%) | There are no costs to you for donating your samples and information to the Biorepository. |  |
| 126ab454d7e-cb0a-462d-ada1-ee36039e14e1 | Not Translated (0%) | You will not be paid for donating your samples or health information. |  |
| 127244798f3-acbd-403a-8184-50840e343f6a | Not Translated (0%) | If new product, drug or medical test is developed using your sample or information, it may be sold for profit. |  |
| 128d3d51f12-aeac-4690-8a6a-7cbae4820e66 | Not Translated (0%) | If this happens, you will not share in that profit. |  |
| 1292e229d01-6167-474e-a7bb-fbce68a521ca | Not Translated (0%) | St. Jude may sell your samples and health information to commercial companies that conduct research or develop new drugs, devices, tests. |  |
| 130f5a53d6e-c72c-4100-beca-b9ef163a959c | Not Translated (0%) | You will not receive any payment from the sale of your samples and information. |  |
| 1313b30581d-92bb-47b5-9f7f-0ccb3cd3b686 | Not Translated (0%) | Samples or information that are sold will not include identifying information. |  |
| 13231d76021-fa85-44dc-bf22-3108b7d94e2a | Not Translated (0%) | <88>Permission to Use Your Data/Information:</88> |  |
| 133507a454a-bbaf-4c4a-ad0c-d67f5e0b662e | Not Translated (0%) | <91>Authorization/HIPAA</91> |  |
| 13424b48593-3afe-42d8-8869-2a1b843b713a | Not Translated (0%) | If you sign this document, you give permission to the St. Jude Biorepository to use or disclose (release) your health information as described in this document. |  |
| 135149c6dba-08fb-45cd-bf90-f7b89cea603d | Not Translated (0%) | With approval of the St Jude Institutional Review Board, the health information associated with you and your tissue samples that the Biorepository may use or disclose (release) for research purposes includes information related to your medical history, diagnosis, laboratory test results, x-rays, scans, medical procedures, diagnostic testing results treatments and medications. |  |
| 1369363b029-7afd-4bd6-b42c-833263348e3d | Not Translated (0%) | The health information may be used by and/or disclosed (released) to researchers and their staff at St. Jude Children’s Research Hospital as well as researchers around the world and commercial companies. |  |
| 1371e06fe19-427b-465c-8859-383e3f8d01f7 | Not Translated (0%) | The choice to donate your samples and health information is up to you and will not affect your treatment in any way. |  |
| 138a77f1257-8eb2-4d5b-866f-ecd89db47b14 | Not Translated (0%) | Those persons who receive your health information may not be required by Federal privacy laws (such as the Privacy Rule) to protect it and may share your information with others without your permission, if permitted by laws governing them. |  |
| 139d9726332-8d3f-4e7d-8b84-e6dbcbdf76cd | Not Translated (0%) | You do not have to sign this Authorization, but if you do not, you cannot donate samples and information to the St. Jude Biorepository. |  |
| 1406a43ce7f-20bd-4486-8afd-ac1353d504db | Not Translated (0%) | You may change your mind and revoke (take back) this Authorization at any time, and request that your tissue samples be removed from the Biorepository and destroyed. |  |
| 14136902d1a-9f67-4059-9b7b-8ef30b6b6642 | Not Translated (0%) | Even if you revoke this Authorization, health information already provided to researchers cannot be retrieved. |  |
| 1425f77e723-5e7a-4f77-9831-9caf7b749994 | Not Translated (0%) | To revoke this Authorization, you must write to: |  |
| 143aeba73ea-c9de-44ec-bd16-09a57ba0e612 | Not Translated (0%) | HIPAA Privacy Officer |  |
| 1448202b894-aa84-4d41-889d-056f3b9e556b | Not Translated (0%) | St. Jude Children's Research Hospital 262 Danny Thomas Place, Mail Stop 280 Memphis, TN 38105 |  |
| 145717986f5-b211-44cd-bdba-0ba670bb7b48 | Not Translated (0%) | This Authorization does not have an expiration date. |  |
| 146e1c9ab1e-4084-4672-a64e-b374141a9681 | Not Translated (0%) | <94>PARENT/GUARDIAN STATEMENT (Required for participants younger than 18 years):</94> |  |
| 147b7fadeec-dadc-420b-ab2b-55d5cf673382 | Not Translated (0%) | I have read this document, or it was read to me. |  |
| 148784ad027-28a8-4fdc-858f-30484f10ee88 | Not Translated (0%) | I have been encouraged to ask questions and all my questions have been answered. |  |
| 1496a024fb0-8bce-4217-aace-cbc72d0ff200 | Not Translated (0%) | I give permission for my child to donate to the St. Jude Biorepository. |  |
| 15051c8db91-7c3d-45d2-a7ec-16b69ee50376 | Not Translated (0%) | <99><96/><97/> </99><100/>AM/PM |  |
| 1519085cc9d-87d0-4fc7-90f5-d96474e5c6cc | Not Translated (0%) | Parent/Legal Guardian Signature |  |
| 1529e6dd733-860d-4d5e-8dde-42bbfd78842c | Not Translated (0%) | Date |  |
| 153a82d2085-eae9-4f48-8593-16ecb9258c12 | Not Translated (0%) | Time (circle one) |  |
| 1545ccca24c-c3a1-4743-8c92-ca864976feb5 | Not Translated (0%) | <103>ASSENT DISCUSSION (Required for participants 7-13 years old)</103> |  |
| 155c57d7d7c-bef7-4a0e-b6ea-8f19cd21e679 | Not Translated (0%) | The Biorepository was explained to the minor participant in age-appropriate terms and the minor verbally agreed to donate samples and information to the Biorepository. |  |
| 1566a2ffaf6-99f7-44f4-bfc4-6c22b64df463 | Not Translated (0%) | Minor declined to allow their samples and health information be donated to the Biorepository. |  |
| 15753e75f2e-b3c4-4810-9c9d-96969062c711 | Not Translated (0%) | The minor declined for the following reason(s): |  |
| 1587341f13c-3149-4fe0-a63b-3b0f49570db8 | Not Translated (0%) | An assent discussion was not initiated with the minor for the following reason(s): |  |
| 1599dc9b429-8d8a-4033-9e24-fb49e9f22619 | Not Translated (0%) | Minor is under 7 years of age. |  |
| 160d79bc0ed-1fcb-42e5-8748-eed47e09ea2d | Not Translated (0%) | Minor is incapacitated. |  |
| 1611923b911-29e3-46a4-9d46-2133d5a7193e | Not Translated (0%) | Minor refused to take part in the discussion. |  |
| 162134646f8-0672-4952-b6e9-233cab8e1617 | Not Translated (0%) | Other<106> </106><110><108/></110> |  |
| 163f056490c-2f4a-4a9e-8e0a-3d2630726958 | Not Translated (0%) | <113>PARTICIPANT STATEMENT (14-17 years old and Adult Participants 18 years and older):</113> |  |
| 164782ee614-ecc2-4660-8c79-c9e3c5ddfa7b | Not Translated (0%) | I have read this document or it was read to me. |  |
| 165137edb9b-3e53-438f-8132-5ebb0b0d9ffb | Not Translated (0%) | I have been encouraged to ask questions and all my questions were answered. |  |
| 166b8442ae9-5e78-4bda-9cb2-d88983f21c23 | Not Translated (0%) | I agree to donate samples and information to the Biorepository. |  |
| 1674ebb734e-9571-41ff-b80a-effb6c56132b | Not Translated (0%) | <118><115/><116/> </118><119/>AM/PM |  |
| 16860b96fb0-640a-4e13-88ab-6e8013e8ddfc | Not Translated (0%) | Participant Signature |  |
| 1693feca5ef-a6ce-4bbf-91a1-564a0bbc7107 | Not Translated (0%) | Date |  |
| 170b6533f33-62f9-4ba1-9302-0a76b395f151 | Not Translated (0%) | Time (circle one) |  |
| 171bcfe1aa9-adbe-48bf-a6cc-8ec3efc94fc6 | Not Translated (0%) | <122>RESEARCHER/DESIGNEE STATEMENT:</122> |  |
| 172fc1f3328-477e-4ba0-815c-b4a8a7da30ca | Not Translated (0%) | I have explained the Biorepository to the participant and his/her parent(s) or legal guardian(s). |  |
| 173dc81f2d0-7c27-4709-a1a2-bd948beae8dd | Not Translated (0%) | The participant and parent(s)/guardian(s) were encouraged to ask questions and all questions were answered to their satisfaction. |  |
| 1747dcf65e8-d4fb-4f67-a91f-93347c06b237 | Not Translated (0%) | A copy of this form has been given to the participant or his/her representative. |  |
| 17588f7d06d-fdfc-41b6-b325-8282ea7813e8 | Not Translated (0%) | <127><124/><125/> </127><128/>AM/PM |  |
| 1766c6e36c3-be73-4b83-bc6e-7958735c00eb | Not Translated (0%) | Research/Designee Signature |  |
| 177f3032441-4354-43e1-9e65-d1b311c25c0c | Not Translated (0%) | Date |  |
| 178b2872283-c19b-45de-b6d8-8377944d216a | Not Translated (0%) | Time (circle one) |  |
| 1791ff8e655-2857-4991-9a15-c042dbfae2d2 | Not Translated (0%) | Print Name |  |
| 180db064a29-ecf5-46d6-bd0d-8c2ce5067807 | Not Translated (0%) | <133><130/><131/> </133><134/>AM/PM |  |
| 1815ae4837a-3855-4009-bb12-b2f5bb0b3f13 | Not Translated (0%) | Interpreter (if needed) |  |
| 182b3133762-3850-4827-ae76-d9aeab4bbdc0 | Not Translated (0%) | Date |  |
| 183e652823f-9cf1-4b7a-bda6-0ea64ab91e57 | Not Translated (0%) | Time (circle one) |  |
| 1843680f5a8-dcf0-4107-b557-d19c1a103f89 | Not Translated (0%) | PLEASE FAX CONSENT FORM TO PROTOCOL OFFICE #6265 |  |
| 1856277129a-fdde-4e1e-a97e-60d6da78e8d3 | Not Translated (0%) | Revision 3.2 dated: |  |
| 18664c4d818-a373-4a30-8afe-aee29ba01da1 | Not Translated (0%) | 06-13-2019 |  |
| 187070b6b74-763b-44c9-a49b-33d23ef0cd2e | Not Translated (0%) | Consent doc. date: |  |
| 1886fb50942-7839-4ae9-8493-73de9d34cb98 | Not Translated (0%) | 06-13-2019 |  |
| 1896ffd72bc-2a5e-4884-8579-ed9b699105f8 | Not Translated (0%) | Research Participant ID #: |  |
| 19007d22032-5db2-4c98-9231-97a05c0a9948 | Not Translated (0%) | Research Participant Name: |  |
| 191ac626a30-1605-4c98-b6d0-47f38566a3e3 | Not Translated (0%) | TBANK |  |
| 192d6ae4b9e-a4d8-4892-aaa8-6879df56d75a | Not Translated (0%) | Page <135/><136/><137/>1<138/> of 5 |  |