

## INFORMED CONSENT FOR DONATION OF CORD BLOOD

### I. BACKGROUND:

Thank you for your interest in donating your baby's cord blood to the Upstate Cord Blood Bank (Bank) program. Currently, there are more than 80 diseases that are being treated with cord blood cells. You have the opportunity to help save the life of someone who needs cord blood cells by donating. Before you decide to donate, you need to understand how the process works.

### II. YOUR DECISION TO DONATE:

All delivering mothers are invited to donate their baby's cord blood. If you decide to participate, you are agreeing to the collection, processing, testing, storage, registry listing, and distribution of your baby's cord blood unit (CBU). Your baby's cord blood will be listed with a Registry for treatment of patients if it meets all the required criteria. Cord blood that is processed and stored for patient use will be stored until needed by a patient. This cord blood unit may be available for your child or family if needed in the future, but this cannot be guaranteed. If your cord blood is not appropriate for patient treatment, we ask your permission to use the cord blood for research. Cord blood which does not meet criteria will be stored only until provided to a researcher or used internally at the Cord Bank.

### III. THE DONATION PROCESS:

If you agree to donate your baby's cord blood, you must be willing to answer personal questions about your medical history, genetic history, sexual and social history, and health history of the biological father and his family. You can refuse to answer any question; however, it will disqualify your baby's cord blood.

On admission, five (5) tubes of blood will be drawn from you and tested for certain infectious diseases and we will test your baby's cord blood for blood cell and tissue typing. There is certain information we are required to collect that is in your and/or your baby's hospital medical record. We may need to contact you directly for information regarding infections and congenital anomalies after the birth of your baby.

### IV. POSSIBLE RISKS AND BENEFITS OF DONATION:

The only possible direct benefit to you or your baby from donating cord blood is that you might learn of an infection that may benefit from early treatment.

No blood is taken from your baby. When taking blood from your arm you may experience discomfort and/or bruising. If our testing uncovers an abnormal result for you or your baby, we may need to contact your provider for further evaluation and/or treatment for you and your baby. In addition, if required by federal, state or local law, some positive results may be reported directly to your state health department.

### V. CONFIDENTIALITY:

To protect your privacy, your identity and all information collected from you will be kept confidential and in locked files at the Bank. Only authorized staff will have access to any personal information. No information about you or your baby will be disclosed to anyone unless required by law or upon your request or with your written permission. However, information about your history and the cord blood will be entered in the Registry and identified by a number.

Individuals authorized by the Bank and the Food and Drug Administration will have access to your and your baby's medical records for inspections or audits. If you agree to donate, you consent to such inspections and to the copying of these records, if required.

### VI. CONSENT IS VOLUNTARY AND MAY BE WITHDRAWN:

Your consent to donate your baby's cord blood is your choice. If you choose not to consent, neither your care nor your baby's care will be negatively affected and the placenta and cord blood will be discarded according to the hospital's practice. If you do agree to donate your baby's cord blood, you can change your mind at any time without any consequences by contacting us at 315-492-2600 to stop any further processing. At that point, the cord blood will be destroyed according to the Bank's procedures.

**VII. REIMBURSEMENT AND COSTS:**

Donating your baby's cord blood is free. You will not be charged for any expenses related to the collection of the cord blood and your insurance will not be billed. You will not be paid for donating cord blood.

**VIII. OPTIONAL DONATION FOR FUTURE RESEARCH:**

In addition to using cord blood to treat patients, cord blood can be used to help doctors and scientists learn more about caring for and treating people with cancer and other diseases, such as heart disease and stroke. Only cord blood which cannot be donated to another person will be used for research. If you agree, your baby's cord blood may be used for research if it is not selected for patient treatment. The cord blood may be sent to researchers, be used for equipment testing, used for staff training or may be discarded. The only information that will be provided to researchers is that the sample was collected within 48 hours/or was frozen and that it is not known to be infectious. No results from research tests will be provided to you or your or your baby's provider or added to your medical record.

There is no direct benefit to you or your baby in connection with the donation of your cord blood. There is a small risk that your personal information could be subject to improper release or disclosure. However, all reasonable efforts will be made to protect the confidentiality of information that in any way be connected to you. We will not release your or your baby's name, address or any other identifying information to the researchers. The Bank may charge researchers a fee to recover cord blood collection costs, but you will not receive payments for donating your baby's cord blood for research.

**IX. ALTERNATIVES:**

There are private companies or family banks that will collect, process, and store your baby's cord blood exclusively for your family to use. Upstate Cord Bank is not currently offering this service. If you choose to use one of these family banks, you will need to contact them directly and there is a fee for collection and storage.

**X. QUESTIONS OR CONCERNS:**

If you need more information before you consent to donate, contact us at (315) 492-2600. You may also visit our website [www.upstatecordbloodbank.com](http://www.upstatecordbloodbank.com).

**XI. STATEMENT OF CONSENT FOR RESEARCH:**

I agree \_\_\_\_\_ or do not agree \_\_\_\_\_ that if the cord blood is not acceptable for treatment, the blood can be used for research.

**BY SIGNING BELOW, YOU INDICATE THAT YOU HAVE READ THIS CONSENT FORM, YOU HAVE BEEN GIVEN THE OPPORTUNITY TO ASK QUESTIONS, AND YOU AGREE TO DONATE YOUR BABY'S CORD BLOOD TO THE UPSTATE CORD BLOOD BANK, AND AGREE THAT YOUR OWN AND YOUR BABY'S PERSONAL HEALTH INFORMATION MAY BE COLLECTED, USED, AND SHARED BY AUTHORIZED BANK STAFF FOR PURPOSES DESCRIBED IN THIS FORM.**

\_\_\_\_\_  
*Signature of the Mother on behalf of her baby as Donor*

\_\_\_\_\_  
*Date*

\_\_\_\_\_  
*Print Name of Mother*

\_\_\_\_\_  
*Donor Contact Address*

\_\_\_\_\_  
*Phone Number*

\_\_\_\_\_  
*E-mail Address*

**If an interpreter was used to complete this consent:**

\_\_\_\_\_  
*Signature / Print Name of Interpreter*

\_\_\_\_\_  
*Date*

UCBB Barcode Label