

NOTICE OF PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION.

PLEASE REVIEW IT CAREFULLY.

If you have any questions about this notice, please contact Mr. Richard Hoffine, KCUMB Privacy Officer of our office at 816-283-2305 or in writing at 1750 Independence Ave, Kansas City, MO 64106.

WHO WILL FOLLOW THESE PRACTICES

This notice describes the information privacy practices followed by our employees, staff and other office personnel.

YOUR HEALTH INFORMATION

This notice applies to the information and records we have about your health, health status, and the health care and clinical trial services you receive at this office. We are required by law to give you this notice. It will tell you about the ways in which we may use and disclose health information about you and describes your rights and our obligations regarding the use and disclosure of that information.

HOW WE MAY USE AND DISCLOSE HEALTH INFORMATION ABOUT YOU

We must have your written, signed Consent to use and disclose health information for the following purposes:

- * For Participation in Clinical Trials. We may use health information about you to provide you with medical treatment or services as part of our clinical trials. We may disclose health information about you to doctors, nurses, technicians, coordinators, office staff or other personnel who are involved in conducting our clinical trials.

- * For Treatment. We may use health information about you to provide you with medical treatment or services. We may disclose health information about you to doctors, nurses, technicians, office staff or other personnel who are involved in taking care of you and your health.

For example, to participate in a clinical trial our staff may need to know if you have other health problems that could complicate your participation or include/exclude you from participation. In addition our staff may use your medical history to decide what clinical trial is best for you. The study doctor may also tell another doctor about your condition so that doctor can help determine the most appropriate care for you and make recommendations regarding your clinical trial participation.

Different personnel in our office may share information about you and disclose information to people who do not work in our office in order to coordinate your care, such as phoning in prescriptions to your pharmacy, scheduling lab work and ordering x

rays. Family members and other health care providers may be part of your medical care outside this office and may require information about you that we have.

* For Payment. We may use and disclose health information about you so that you may receive a stipend for your clinical trial participation.

* For Health Care Operations. We may use and disclose health information about you in order to run the office and make sure that you and our other participants receive quality care. For example, we may use your health information to evaluate the performance of our staff in caring for you. We may also use health information about all or many of our participants to help us decide what additional clinical trials we should offer, how we can become more efficient, or whether certain new treatments are effective.

* For Research Purposes. We may use and disclose health information about you to organizations that sponsor our research, organizations that monitor our research and the FDA.

* Appointment Reminders. We may contact you as a reminder that you have an appointment at our office.

* Treatment Alternatives. We may tell you about, or recommend, possible clinical trials options or alternatives that may be of interest to you.

* Health Related Products and Services. We may tell you about health related products or services that may be of interest to you.

Please notify us if you do not wish to be contacted for appointment reminders, or if you do not wish to receive communications about clinical trial alternatives. If you advise us in writing (at the address listed at the top of this Notice) that you do not wish to receive such communications, we will not use or disclose your information for these purposes.

You may revoke your Consent at any time by giving us written notice. Your revocation will be effective when we receive it, but it will not apply to any uses and disclosures that occurred before that time.

If you do revoke your Consent, we will not be permitted to use or disclose information for purposes of treatment, payment or health care operations, and we may therefore choose to discontinue your participation in our clinical trials and any related health care treatment and services.

SPECIAL SITUATIONS

We may use or disclose health information about you without your permission for the following purposes, subject to all applicable legal requirements and limitations:

* To Avert a Serious Threat to Health or Safety We may use and disclose health information about you when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person. Required By Law We will disclose

* Required By Law We will disclose health information about you when required to do so by federal, state or local law.

* Research We may use and disclose health information about you for our research projects that are subject to a special approval process. We will ask you for your

permission to have access to your name, address or other information that reveals who you are, or will be involved in your care at the office.

* **Military, Veterans, National Security and Intelligence** If you are or were a member of the armed forces, or part of the national security or intelligence communities, we may be required by military command or other government authorities to release health information about you. We may also release information about foreign military personnel to the appropriate foreign military authority.

* **Public Health Risks** We may disclose health information about you for public health reasons in order to prevent or control disease, injury or disability, or report births, deaths, suspected abuse or neglect, non accidental physical injuries, reactions to medications or problems with products.

* **Health Oversight Activities** We may disclose health information to a health oversight agency such as the FDA for audits, investigations, inspections, or licensing purposes. These disclosures may be necessary for certain state and federal agencies to monitor the health care system, government programs, and compliance with civil rights laws.

* **Lawsuits and Disputes** If you are involved in a lawsuit or a dispute, we may disclose health information about you in response to a court or administrative order. Subject to all applicable legal requirements, we may also disclose health information about you in response to a subpoena.

* **Law Enforcement** We may release health information if asked to do so by a law enforcement official in response to a court order, subpoena, warrant, summons or similar process, subject to all applicable legal requirements.

* **Coroners, Medical Examiners and Funeral Directors** We may release health information to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or determine the cause of death.

* **Information Not Personally Identifiable** We may use or disclose health information about you in a way that does not personally identify you or reveal who you are.

* **Family and Friends** We may disclose health information about you to your family members or friends if we obtain your verbal agreement to do so or if we give you an opportunity to object to such a disclosure and you do not raise an objection. We may also disclose health information to your family or friends if we can infer from the circumstances, based on our professional judgment that you would not object. For example, we may assume you agree to our disclosure of your personal health information to your spouse when you bring your spouse with you into the exam room during your clinical trial participation where your participation is being discussed.

In situations where you are not capable of giving consent (because you are not present or due to your incapacity or medical emergency), we may, using our professional judgment, determine that a disclosure to your family member or friend is in your best interest. In that situation, we will disclose only health information relevant to the person's involvement in your care. For example, we may inform the person who accompanied you to the emergency room that you suffered a heart attack and provide updates on your progress and prognosis. We may also use our professional judgment and experience to make reasonable inferences that it is in your best interest to allow another person to act on your behalf to pick up, for example, filled prescriptions, medical supplies, or X rays.

OTHER USES AND DISCLOSURES OF HEALTH INFORMATION

We will not use or disclose your health information for any purpose other than those identified in the previous sections without your specific, written Authorization. We must obtain your Authorization separately or as part of a general or specific consenting process. If you give us Authorization to use or disclose health information about you, you may revoke that Authorization, in writing, at any time. If you revoke your Authorization, we will no longer use or disclose information about you for the reasons covered by your written Authorization, but we cannot take back any uses or disclosures already made with your permission.

YOUR RIGHTS REGARDING HEALTH INFORMATION ABOUT YOU

You have the following rights regarding health information we maintain about you:

* **Right to Inspect and Copy** You have the right to inspect and copy your health information, such as our participant study files, and payment records, that we use to make decisions about your care and/or your participation. You must submit a written request in order to inspect and/or copy your health information. If you request a copy of the information, we may charge a fee for the costs of copying, mailing or other associated supplies. We may deny your request to inspect and/or copy in certain limited circumstances. If you are denied access to your health information, you may ask that the denial be reviewed. If such a review is required by law, we will select a licensed health care professional to review your request and our denial. The person conducting the review will not be the person who denied your request, and we will comply with the outcome of the review.

* **Right to Amend** If you believe health information we have about you is incorrect or incomplete, you may ask us to amend the information. You have the right to request an amendment as long as the information is kept by this office.

To request an amendment, complete and submit a Medical Record Amendment/Correction Form to Mr. Richard Hoffine, KCUMB Privacy Officer. We may deny your request for an amendment if it is not in writing or does not include a reason to support the request. In addition, we may deny your request if you ask us to amend information that:

1. We did not create, unless the person or entity that created the information is no longer available to make the amendment.
2. Is not part of the health information that we keep.
3. You would not be permitted to inspect and copy.
4. Is accurate and complete.

* **Right to an Accounting of Disclosures** You have the right to request an "accounting of disclosures." This is a list of the disclosures we made of medical information about you for purposes other than clinical trial eligibility and/or participation, payment and health care operations. To obtain this list, you must submit your request in writing to the Privacy Board Chair. It must state a time period, which may not be longer than six years and may not include dates before April 14, 2003. Your request should indicate in what form you want the list (for example, on paper, electronically). We may charge you for the costs of providing the list. We will notify you of the cost involved and you may choose to withdraw or modify your request at that time before any costs are incurred.

* **Right to Request Restrictions** You have the right to request a restriction or limitation on the health information we use or disclose about you for clinical trial eligibility and participation, payment or health care operations. You also have the right to request a limit on the health information we disclose about you to someone who is involved in your care or the payment for it, like a family member or friend. For example, you could ask that we not use or disclose information about a surgery you had.

* **We are Not Required to Agree to Your Request** If we do agree, we will comply with your request unless the information is needed to provide you emergency treatment.

To request restrictions, you may complete and submit the Request For Restriction On Use/Disclosure Of Medical Information to Mr. Richard Hoffine.

* **Right to Request Confidential Communications** You have the right to request that we communicate with you about medical matters in a certain way or at a certain location. For example, you can ask that we only contact you at work or by mail.

To request confidential communications, send your written request to, Mr. Richard Hoffine. We will not ask you the reason for your request. We will accommodate all reasonable requests. Your request must specify how or where you wish to be contacted.

* **Right to a Paper Copy of This Notice** You have the right to a paper copy of this notice. You will be given a copy of this notice at your first visit. You may ask us to give you a copy of this notice at any time. Even if you have agreed to receive it electronically, you are still entitled to a paper copy.

CHANGES TO THIS NOTICE

We reserve the right to change this notice, and to make the revised or changed notice effective for medical information we already have about you as well as any information we receive in the future. We will post a summary of the current notice in the office with its effective date in the top right hand corner. You are entitled to a copy of the notice currently in effect.

COMPLAINTS

If you believe your privacy rights have been violated, you may file a complaint with our office or with the Secretary of the Department of Health and Human Services. To file a complaint with our office, contact Mr. Richard Hoffine, KCUMB Privacy Officer of our office at 816-283-2305 or in writing at 1750 Independence Ave, Kansas City, MO 64106. You will not be penalized for filing a complaint.

For additional information, please contact CRC.