

## Frequently Asked Questions

**Q: What is a paraffin tissue block?**

A: It's a small one inch block of wax, with a piece of tumor inside. A tumor may yield 1-20 tissue blocks, depending on the size. From one block you can make at least 200 slides. These blocks are made routinely after each surgery and stored in the hospital's pathology lab for 10 years or more.

**Q: What is required of me to donate a paraffin tissue block to the bank?**

A: You must read the "Leiomyosarcoma Tissue Bank Consent. Next, sign the "Donor Signed Request for Transfer of Paraffin Block." Send this signed form to Sharon Anderson. You will then be interviewed by phone to obtain your medical history pertaining to leiomyosarcoma, (if you have checked the "Yes" on the Donor Request form.) You might be asked to participate in a follow-up phone interview a few years later.

**Q: Will this cost me anything?**

A: No.

**Q: Will I be able to get information about my own tissue sample from the researcher?**

A: No. The researcher cannot have access to the donors' names.

**Q: If I've already donated a tissue sample between 2004-2012, should I donate again?**

A: No. Your tissue is still part of this tissue bank.

**Q: Do you want ALL my paraffin tissue blocks?**

A: No. We are collecting one sample from your **primary tumor**, but are also interested in blocks from recurrent tumors and metastases. Typically there are many paraffin blocks made from one tumor.

**Q: Do I need to get my doctor's permission to participate?**

A: No.

**Q: Do I need to contact my hospital pathology laboratory where the samples are?**

## Leiomyosarcoma Paraffin Tissue Block Repository

A: No, please do not contact anyone. We will obtain the sample for you, using your signed "Donor Signed Request" form.

**Q: Can a tissue sample be donated after an LMS patient has died?**

A: Yes. The hospital might request documentation of Power of Attorney to be sent. If you have this, please send it to us with the other form.

**Q: Can I change my mind and have my sample returned to my hospital?**

A: Yes. You will need to do so in writing to Sharon Anderson who will communicate with the van de Rijn lab, using the de-identified number of the block, to retrieve the block and return it.

**Q: How will I know you received my tissue sample?**

A: After your sample arrives, we will phone you to get your medical history. Not all hospitals comply with our request for a sample. If we cannot obtain a sample, we will let you know by phone. Please allow several weeks before inquiring.

**Q: Why do you need to get my medical history over the phone?**

A: Your medical history informs researchers about the tumor sample; for example if you had radiation or a chemo before surgery. We have found in the past, that these details are more convenient to get over the phone, rather than have donors fill out long forms. All information is confidential and names are never released to researchers.

**Q: Who owns this tissue bank?**

A: Patients own their own tissues. Dr. Matt van de Rijn is the curator of the donor's tissues which are housed in his laboratory at Stanford University Medical Center.

**Q: How will these tissue samples be shared with other researchers?**

A: Researchers can contact Dr. Matt van de Rijn. A scientific advisory committee will oversee and insure that these valuable samples be shared for only worthy projects and not wasted.

**Q: What kind of research is possible with the paraffin tissue blocks?**

A: Molecular and genetic study.

**Q: Who do I contact if I have more questions?**

A: Sharon Anderson at [2SharonAnderson@gmail.com](mailto:2SharonAnderson@gmail.com) or Tel. 650-922-8762.

## Leiomyosarcoma Paraffin Tissue Block Repository

Sharon is a social worker, LMS advocate and 11 yr. survivor. She is volunteering as Tissue Coordinator under the guidance of Dr. Matt van de Rijn at Stanford University where the Leiomyosarcoma Paraffin Tissue Block Repository is located. As a liaison, Sharon will be bridging the gap between tissue donors and researchers, to assure anonymity and confidentiality.