

Information and Instructions About Participating in Merkel Cell Carcinoma Research

Thank you for your interest in participating in our Merkel cell carcinoma (MCC) research. As you may know, MCC is a rare skin cancer with only about 1500 cases per year in the United States. Currently, there are no clear guidelines about how patients should be best managed, and as a result, patients are being treated with different combinations of surgery, chemotherapy and radiation therapy. Further, little is known about what causes this cancer, and no effective therapies exist for advanced disease. Thus, we are conducting both clinical and basic science research to better understand MCC.

Please note that we are only gathering your clinical information, tumor samples and blood for research purposes and will not be using your information to make treatment recommendations or serve as consultants in your care. If you wish to be seen in our clinic, please contact our scheduler at the Seattle Cancer Care Alliance at (206) 288-1024. You can participate in our research whether or not you are seen in our clinic. If you have not been seen in our clinic, we cannot provide you treatment recommendations beyond the information we have posted at www.merkelcell.org. Treatment advice can only be properly given by your treating physician.

Research Overview

We have created a research program that includes both clinical and basic science studies. We have a database of clinical information (i.e. medical records) and a tissue and blood bank that contains samples from patients with MCC. These will be used to study what causes this cancer and to find better treatments for MCC.

Who Can Participate?

Any adult with Merkel cell carcinoma who has received medical care in the US can participate. Participation in our research is ***completely voluntary***.

Participation Overview

You can participate by sharing one or more of the following:

- Clinical data - you can be added to our clinical patient database by sending us information from your medical records regarding your diagnosis and treatment of MCC
- Tumor tissue left-over from your initial biopsy - with your permission, we will request a portion of your original biopsy (that is now stored in a pathology lab) be sent to us for research purposes
- Tumor tissue left-over from a future biopsy or excision - if you have not had your tumor completely removed yet or should it recur, you can have a left-over portion of your tumor sent to us at the time of surgery
- Small sample of blood - you can have a small amount (about 5cc or 1teaspoon) of blood drawn and sent to us

Instructions for Participation

The first step is informed consent. Informed consent involves reading the consent form, discussing the research with a member of our study team, having all of your questions answered and then signing the consent form if you agree to participate.

There are two ways for us to do informed consent:

1. Read the consent form, sign and mail (or fax) it to us, and when we receive it we will call you to discuss the study and answer any questions.
2. Read the consent form, call us to discuss the study, ask any questions you have, then sign and mail (or fax) the form to us.

The last page of the consent form includes checkboxes for you to indicate in which portions of the research you wish to participate.

You must also read, sign and date the "University of Washington Authorization to Use, Create and Share Health Information for Research." This form can then also be mailed or faxed to use.

Once the informed consent process is complete, we will provide the details of how to send us records, tumor samples, and/or blood.

Thank you for your interest in participating in Merkel cell carcinoma research.

Please do not hesitate to contact us with any questions.

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(We cannot provide medical advice to patients we have not seen.)

Summary

After you read and understand the forms, send the following items by mail or fax:

- 1) Page 3 (last page) of the Consent Form, after signing/completing
- 2) "University of Washington Authorization to Use, Create and Share Health Information for Research" Form, after signing