

Flat-Coated Retriever Cancer Studies Frequently Asked Questions about Study Participation

Q: What is the difference between malignant histiocytosis and histiocytic sarcoma? Are these diseases known by any other names?

A: The terms malignant histiocytosis and histiocytic sarcoma are often used interchangeably. In both cases, specialized cells of the immune system (called histiocytes) undergo uncontrolled cell division (i.e., become malignant). The term histiocytic sarcoma is usually used when the cancer originates at one specific site, whereas the disease is referred to as malignant histiocytosis when it occurs independently at multiple sites throughout the body. Malignant histiocytosis may also be called poorly differentiated sarcoma, undifferentiated sarcoma or fibrous malignant histiocytosis.

Q: What is a soft tissue sarcoma?

A: A soft tissue sarcoma is a malignant growth originating in any type of soft tissue, such as organs (e.g., liver, spleen, lungs, kidney, stomach, heart, pancreas), muscles, blood vessels and connective tissues. Two common examples of soft tissue sarcomas are hemangiosarcoma and fibrosarcoma. There are many other kinds. If you are uncertain whether your dog's cancer is a soft tissue sarcoma, please contact Dr. Breen or the Support Team.

Q: What types of cancer are not of interest to the current studies?

A: Cancers not currently being studied include osteosarcoma, lymphoma, adenocarcinoma, mast cell tumors and squamous cell carcinomas. Note that malignant histiocytosis can affect bone, and it can cause skin lesions. Thus, only a pathologist can distinguish the different types of cancer; the location of the cancer in itself is not always informative.

Q: My dog has cancer, but I don't what kind, and my vet is advising against surgery. Is there any way I can still participate?

A: Dr. Breen is willing to accept tumor samples from undiagnosed cancers. Dr. London sometimes does so as well, though she may wish to speak with your vet before making a decision. If Dr. Breen receives samples from an undiagnosed cancer, and his pathology indicates malignant histiocytosis, then he will send Dr. Ostrander the blood DNA she needs.

Q: Is there any way to get a diagnosis without doing surgery?

A: The first indication that your dog has cancer often comes from X-rays or ultrasound imaging. These may indicate the presence of cancer, though they will not reveal the type of cancer. If the tumor is on or near the surface of the skin, then a simple punch biopsy can generate enough cells for a pathologist to analyze. In cases where the mass is internal, diagnosis is sometimes carried out through the collection and analysis of a fine needle aspirate of cells from the core of the mass. Punch biopsies and fine needle aspirates can often be done with only local anesthesia and/or sedation.

Q: Should I subject my dog to surgery just to collect the tumor samples needed for the research studies?

A: Absolutely not! We do not recommend putting your dog through surgery or any other invasive procedure purely for the purpose of study participation. The research studies are important, but your dog's health and comfort are more important. There are three potential opportunities for tissue collection: (i) at the time a biopsy is taken for diagnostic purposes, (ii) during surgery to remove the tumor, and (iii) after the dog been euthanized. The majority of samples are collected postmortem.

Q: If I know or suspect that my dog has cancer, whom should I contact first?

A: Your vet should always be your first contact. But if you and your vet think that your dog has cancer, then we suggest that you contact the Support Team (FCR-Cancer-Support@yahoogroups.com). We can help you identify the studies for which your dog is eligible, and we can guide you and your vet through the process of study participation. We can contact the researchers and make any necessary arrangements. We can offer advice on how to keep your ailing dog comfortable. Also, since we understand what you are going through (we have all been there ourselves), we may be able to provide much-needed emotional support. However, if you prefer, you may contact the researchers directly and handle the arrangements yourself; the researchers will welcome your inquiries.

Q: What happens when I send a message to the Support Team group address? Is the information I share confidential?

A: When you send a message to the Support Team, all members of the Team (currently 6 people) receive that message. We then make a decision as to which Team member will help you; from that point on, your correspondence will be with an individual member. Any information you provide is shared only with the researchers and with other Support Team members, as needed. We consult often with each other because our collective expertise and experience is greater than that of any one individual. If we need to share information with someone other than a researcher or another Team member (e.g., to track down pedigree information), we will seek your permission before doing so.

Q: My dog has a little lump on his skin. I am going to have it removed, just to be safe. Should it be sent to one of the researchers?

A: A small cutaneous mass should not be submitted for study for a couple of reasons. First, when dealing with a small mass, it is important that all the tissue that was excised be sent for pathological analysis to determine whether clean margins were obtained (i.e., whether the entire mass was removed). Also, a single small skin lump is unlikely to be a soft tissue sarcoma or malignant histiocytosis.

Q: How big does my dog's tumor have to be in order to generate enough tissue for the researchers?

A: Even a tumor as small as a pea will generate enough tissue for Dr. Breen's study. Dr. London requires about ten times as much material. Thus, the tumor must be about as big as a walnut, or bigger, to generate enough tissue for both studies. If the samples are being collected during surgery to remove the tumor (i.e., for curative purposes), it is important that samples be sent to a pathology lab to determine whether clean margins were obtained. Thus, your vet will need to exercise his own discretion in determining whether a section of the tumor can be sent to the researchers without compromising the pathology that needs to be done. This concern obviously does not apply if tumor samples are collected postmortem.

Q: Must tumor samples be collected on certain days of the week? How soon must they be shipped?

A: For Dr. London, samples can be collected any day of the week. However, it is critical that she receive the samples 24-36 hours after they are shipped (on ice). Thus, samples must be sent Monday-Thursday for Tuesday-Friday deliveries. Samples collected Friday-Sunday should be stored in the freezer until they can be shipped on Monday.

Dr. Breen's study needs are more time sensitive. Because he requires living cells, he must receive samples 24-36 hours after they are collected. Thus, samples should be collected Monday-Thursday for Tuesday-Friday deliveries. If samples are collected on Friday, it may be possible to make arrangements with Dr. Breen to receive the samples on Saturday. Samples harvested on a weekend, and therefore not shipped until Monday, will no longer be viable by the time Dr. Breen receives them. However, it will still be possible to obtain DNA from the cells, which will allow Dr. Breen to do much of his analysis. Thus, it is still worth contributing tumor samples to Dr. Breen even if they must be collected on a weekend.

Q: Is a kit absolutely required? Can my vet collect samples without a kit?

A: A kit is absolutely required for participation in Dr. London's study, but not for the other two studies. For Dr. Breen's study, your vet will have on hand tubes for blood collection and formalin for preparing fixed tumor samples. The non-fixed tumor sample can be provided in an empty sterile tube. For Dr. Ostrander's study, your vet may use the blood collection tubes available in his office.

Q: If I get a kit in advance, how should it be stored, and how long will it last?

A: Dr. Ostrander's kit is stable indefinitely at room temperature. When Dr. London's kit is received, the tubes should be placed in the fridge (where they are stable indefinitely) and the ice packs stored in the freezer, until you are ready to use them. The tubes in Dr. Breen's kit contain a transport medium for sending unfixed tumor samples; proper storage depends on how soon they will be used. The transport medium is stable for 6 months in the freezer or two weeks in the fridge. If the medium is frozen, then it should be thawed slowly (i.e., in the fridge). The ice packs should be stored in the freezer.

Q: Should I make any special arrangements with my vet for tumor sample collection?

A: If you are planning to have tumor samples collected during surgery, give your vet copies of the relevant vet flyers a day or two in advance so he can study them. In addition, Dr. Breen and/or Dr. London will want to speak with your vet to provide instructions and answer questions. As soon as surgery is scheduled, contact the researchers and ask them to call your vet. Or you may ask the Support Team to contact the researchers for you.

If you are planning to have tumor samples collected at the time of euthanasia, then we recommend a couple of additional steps. First, ask your regular vet to share the study information with the other vets in his practice, in case he is not on duty on the day you have to put your dog to sleep. Second, prepare for the possibility that your regular vet office will be closed when the time comes to let your dog go. Investigate emergency clinics in your area (open 24 hours a day, 7 days a week) and speak with them about the research study needs. Keep copies of the vet flyers at your home and in your car so you will have them with you, regardless of when and where the samples have to be collected.

Q: What are the biggest problems encountered in terms of study participation?

A: In the majority of cases, tumor samples are collected at the time of euthanasia. Since it is difficult to predict when you will need to put your dog to sleep, owners are often unprepared. As noted above, we recommend that you make arrangements in advance both with your regular vet practice and with an emergency clinic. In addition, we recommend that you have the kits sent to your home, so you will have access to them even at times when your regular vet hospital is closed. The kits are stable for months, so you should ask for them to be sent far in advance of when you expect to need them, to eliminate any risk of being unprepared. The Support Team has prepared a special set of instructions for owners planning to have tumor samples collected postmortem. These can be downloaded from this web site; see links on the page called Cancer Research Studies and under Veterinarian Information for Dr. Breen (or London).

One problem Dr. Breen has encountered is that samples collected postmortem are often not sterile; they are contaminated with bacteria or fungi. It is therefore important that your vet have an opportunity to study the research flyers carefully and to speak with Dr. Breen (or a Support Team member, if Dr. Breen is not available) before collecting.

Some vets are unwilling to take time out of their busy schedules to perform a procedure with which they are unfamiliar. That is why it is important to discuss the study needs with your vet in advance. If your vet is unwilling or reluctant to help, find someone who is willing. If you have trouble finding someone, contact the Support Team.

Q: I have to put my dog to sleep sooner than I expected. I'd like to participate, but I don't have anything prepared. What should I do?

A: Contact the Support Team immediately! We have dealt with this situation many times, and we have developed strategies to help you participate if you so choose. We can help you determine which studies are practical under the circumstances, and we can guide you and your vet through the process.

Q: My vet has already begun chemotherapy. Can I still participate?

A: Dogs on chemotherapy or radiation therapy are still eligible to participate in the studies of Dr. London and Dr. Ostrander. They are not eligible for Dr. Breen's study.

Q: I can't find my dog's pedigree. Can I still participate?

A: The chances of your being able to participate are excellent. The best thing to do is to contact your breeder, who will almost certainly be able to provide a pedigree. If you have lost touch with your breeder, contact the Support Team. We may be able to find your breeder or to generate a pedigree from existing data bases.

Q: Dr. Breen wants blood from first-degree relatives. What is a first-degree relative?

A: First-degree relatives include your dog's parents, his offspring and his brothers and sisters.

Q: What if my dog passes away at home? Can I still participate?

A: For Dr. London's study, tumor samples must be collected within an hour (two hours maximum) after death. For Dr. Breen's study, tumor samples ideally should be collected within 8 hours (24 hours maximum) after death. Since it can be difficult to collect blood postmortem, it is wise to have blood collected in advance.

Q: Where do I get the pathology report that the researchers need?

A: After a sample of your dog's tumor is collected, your vet will send the sample to a pathology lab to determine whether your dog has cancer and, if so, what kind. The pathologist then sends a report to your vet, who can give you a copy to send to the researcher(s). Alternatively, your vet can fax the report to the researchers as long as your name and your dog's name are clearly indicated.

Q: My dog's blood count is low, and my vet advises against drawing all the blood requested by the researchers. Can my dog still participate in the studies?

A: Only Drs. Breen and Ostrander need blood; both can make do with fairly small amounts (2 mls) if necessary. If only a small amount of blood is drawn, it is important that it be collected in a small (e.g., 2-3 ml) blood collection tube, so it is not overly diluted by the preservative.

The researchers can also obtain blood DNA from the Animal Health Trust if your dog has previously donated blood to the Flat-Coated Retriever DNA bank.

Blood can sometimes be collected immediately prior to or after euthanasia. If blood is simply not available, then the required DNA can be obtained from a skin punch biopsy collected postmortem.

Q: When is the best time to have blood collected from my dog, relative to surgery, diagnosis, etc.?

A: Dr. Ostrander needs only blood, which should be collected soon after a diagnosis is made. For Dr. Breen's study, it is preferred that the blood be sent together with tumor specimens. It is wise to collect blood in advance of tissue collection, in case your dog becomes too ill. The blood can be stored in the fridge for 4-5 days or in the freezer for up to a year.

Q: Where can I find the forms that need to be submitted with blood and tissue samples?

A: Dr. Breen requires you to fill out a Consent Form, and Dr. London requires a completed Questionnaire. Both forms can be downloaded from this web site or obtained from the Support Team. Dr. Ostrander's Consent Form is contained in her kit; it can also be obtained from the Support Team.

Q: Are there special shipping requirements for sample submission?

A: For the studies of Dr. London and Dr. Breen, samples must be shipped on ice (or ice packs), and they must be shipped for next-day delivery. Dr. Ostrander's samples can be sent by regular mail.

Q: Can I get reimbursed for the costs associated with study participation?

A: The FCR Foundation will reimburse all owners up to \$100 for tissue samples submitted and up to \$50 for blood samples submitted to any of these studies. Receipts are required. You should contact Cheryl Kistner (kistnec@yahoo.com) with requests for reimbursements.