

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

**Q: What types of cancer are of interest to the current studies?**

A: The cancers being studied include osteosarcoma, lymphoma, hemangiosarcoma, histiocytic sarcoma and malignant histiocytic sarcoma. Note that both of the studies currently collecting samples require a definitive diagnosis (i.e., a pathology report).

**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 look at the cells and 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: 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: 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! You should not put 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 you contact the Cancer Studies Support Team (FCR-Cancer-Support@yahoogroups.com). They can help you identify the studies for which your dog is eligible and can guide you and your vet through the process of study participation. They can contact the researchers and make any necessary arrangements. They can offer advice on

how to keep your ailing dog comfortable. Also, since they understand what you are going through (they have all been there), they 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 4 people) receive that message. The Team then decides which member will help you; from that point on, your correspondence will be with an individual Team member. Any information you provide is shared only with the researchers and, if needed, with other Support Team members. Team members consult often with each other because their collective expertise and experience is greater than that of any one individual. If there is a need to share information with someone other than a researcher or the Support Team (e.g., to track down pedigree information), a Team member will seek your permission before doing so.

**Q. How big does my dog's tumor have to be in order to generate enough tissue for the Breen & Modiano study?**

A: Even a tumor as small as a pea will generate enough tissue. 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: Ideally, tumor samples for the Breen & Modiano study should be collected Monday-Thursday and shipped for overnight delivery on Tuesday-Friday. If samples are collected on a Friday or on a weekend, they should be refrigerated over the weekend and then shipped on Monday to arrive on Tuesday. Samples must be received by Dr. Breen within 24 hours of shipping.

**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. If you are planning to have tumor samples collected at the time of euthanasia, then a couple of additional steps are recommended. 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 in your car and in your wallet, 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, it is a good idea to make arrangements in advance both with your regular vet practice and with an emergency clinic.

One problem Dr. Breen has encountered is that samples that are collected postmortem often are 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 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! The Team has dealt with this situation many times, and they have developed strategies to help you participate if you so choose. They can help you determine which studies are practical under the circumstances and can guide you and your vet through the process.

**Q: My vet has already begun chemotherapy or radiation therapy. Can I still participate?**

A: Dogs on chemotherapy or radiation therapy are still eligible to participate in Dr. Ostrander's study. They are not eligible to submit tumor samples for the Breen & Modiano study. However, Dr. Breen can still use blood from dogs who have had chemotherapy or radiation therapy.

**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. They may be able to find your breeder or to generate a pedigree from existing data bases.

**Q: Breen & Modiano request 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 the Breen and Modiano study, tumor samples ideally should be collected with 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: 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: Both Dr. Ostrander's study and the Breen & Modiano study 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.

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 the Breen & Modiano 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: The Breen & Modiano Study requires you to fill out a Consent Form, and this form 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 Breen and Modiano study, samples must be shipped on ice (or ice packs), and they must be shipped for next-day delivery. Blood samples can be sent to Dr. Ostrander by regular mail; make sure the tubes are in a well-padded container.

**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.