

SAMPLE HANDLING

For Canine NCL- DNA Research & Testing at the University of Missouri

DNA SAMPLING:

Blood Sample - The ideal sample for DNA extraction is 5-10cc's of whole blood, in purple-topped (EDTA) tubes. For very small dogs or puppies, 3ccs should be sufficient. When the sample is placed in the tube, rock it gently a few times to distribute the anticoagulant - do not spin, and do not extract serum. Refrigerate until the sample is shipped.

Tissue Sample - Tissue removed as a result of surgery, or upon death of the dog will provide a large amount of DNA for research. Please discuss this with your vet ahead of time if you intend to do this. (If the dog is to be euthanized, have a blood sample pulled first, if possible, and send both samples.) First choice is organ tissue (spleen, kidney, or liver), muscle tissue, second choice muscle tissue (tongue is acceptable if no necropsy is being done). About a 1" cube is all that is needed - not an entire organ, and one tissue sample is sufficient. Have the tissue removed as soon as possible following death, place into a labeled freezer bag, put that into a second bag, freeze, and ship.

Label sample with the following;
call name - owner's last name
(If samples from several dogs are sent together, number samples and forms)

An **Individual Dog Information Form & Survey** should be completed, and a **pedigree copy** should be included with the sample to tie it in with the correct family. If the dog is not affected but is a relative of an affected, please indicate the relationship.

Testing fee for breeds where a test is available (American Bulldogs, Australian Cattle Dog, Australian Shepherd, Border Collie, Cane Corso, Chihuahua, Chinese Crested, Dachshunds, Golden Retriever, English Setters, & Tibetan Terriers) is \$50 for a suspected affected dog, \$65 to screen a clinically normal dog. Testing fee is payable by credit card (Visa, Mastercard, or Discover only) or check or money order payable to "University of Missouri". Payment should accompany sample. *There is no fee for breeds where no NCL test is available and submission is for research purposes.*

Shipping - Ideally the sample should be shipped immediately. If samples are held for a day or over a weekend, blood must be refrigerated, and tissue samples must be kept frozen. Ship via overnight delivery (US Mail, UPS, FedEx, or others). **Do not send on a Friday** - there will not be anyone to accept the delivery on a weekend, and the sample could be unusable by Monday. Pack in a small insulated container (most vets have these for shipping samples to labs), with one or more cool packs - it is important that samples be kept cool.

The delivery address is: Dr. Gary Johnson - NCL Testing/Research
320 Connaway Hall
University of Missouri
Columbia, MO 65211

DIAGNOSTIC and RESEARCH SAMPLING:

For definitive diagnosis and confirmation of NCL and for research analyses, dog owners or their veterinarians should contact Dr Martin Katz for instructions and a collection and shipping kit. Samples desired include whole blood, skin biopsies, and tissues obtained at the time of euthanasia. Kits need to be available to the veterinarian at the time of sample collection, so please request a kit as far in advance of when the samples will be collected as possible. Dr Katz can be reached by email at KatzM@health.missouri.edu, or by phone at 573-882-8480.

If you need clarification, or have any questions about any of these procedures, please contact Liz Hansen by phone (573-884-3712) or email (HansenL@missouri.edu).

CANINE NCL- DNA RESEARCH

Individual Dog Information

Blood – Tissue – other _____

Breed _____

Family ID code: _____

Registered Name _____ Call name _____

Reg# _____ Birth Date _____ Sex? M – F Neutered/Spayed? Y – N

Sample Submission Date: _____ Color _____

Sample submitted for which research project? Neuronal Ceroid Lipofuscinosis

Owner: name _____ breeder's name _____

address _____ address _____

phone (day) _____ phone _____

phone (eve) _____

fax _____

e-mail _____ e-mail _____

Does this dog exhibit any of the following conditions? (*Please attach history for any Yes answer*)

- | | |
|-----------------------------------|--|
| Y - N Allergies | Y - N Digestive difficulties |
| Y - N Arthritis | Y - N Heart Problems |
| Y - N Autoimmune Disorders | Y - N Hernia (where? _____) |
| Y - N Bite or Tooth Abnormalities | Y - N Reproductive Problems |
| Y - N Cancer / Tumors | Y - N Seizures |
| Y - N Cataracts / Vision Problems | Y - N Skin / Coat Problems |
| Y - N Deafness / Hearing Impaired | Y - N Skeletal Abnormalities (Hip Dysplasia, etc.) |
| other (please list): | Y - N Temperament Problems (shy, aggressive, etc.) |

See following pages for NCL-specific questions – please complete for ALL sampled dogs.

ATTACH PEDIGREE COPY TO THIS FORM

Please circle your response to the following;

- I am / am not willing to provide additional blood samples if needed for research.
- I will / will not consider donation of a tissue sample upon the death of this dog, and will discuss this decision with my veterinarian so that a notation is placed in my file.

I submit this sample and pedigree for the purpose of DNA research; I understand that the identity of dogs and owners participating in the research will not be revealed; and I have supplied complete and accurate information, to the best of my knowledge.

Signed: _____ date _____

Test fee for breeds with known NCL tests (American Bulldog, Australian Cattle Dog, Australian Shepherd, Border Collie, Cane Corso, Chihuahua, Chinese Crested, Dachshund, English Setter, Golden Retriever, Tibetan Terrier) is \$50 for dogs with clinical signs suggesting NCL, \$65 for clinically normal dogs. All other breeds are for research only, and there is no participation fee for sending these samples.

PAYMENT INFORMATION:

Check or money order payable to "University of Missouri" enclosed

OR Charge to VISA-MasterCard-Discover Card# _____

Cardholder name: _____ Exp Date: _____

Canine NCL-specific Questionnaire

Has this dog been diagnosed as likely to be affected with NCL? Yes No

Have any relatives of this dog been diagnosed with NCL? Yes No Don't Know

If yes, which relatives? Sire Dam Sibling Offspring Other _____

Paternal Grandsire Paternal Grand-dam Maternal Grandsire Maternal Grand-dam

When is the best time to reach you by phone? _____

Veterinary Contact Information

Primary Care

Vet Name _____

Clinic Name _____

Address _____

City,St,Zip _____

Phone # _____

Email _____

Ophthalmologist

Name _____

Clinic Name _____

Address _____

City,St,Zip _____

Phone # _____

Email _____

Neurologist

Vet Name _____

Clinic Name _____

Address _____

City,St,Zip _____

Phone # _____

Email _____

Other Specialist

Name _____

Clinic Name _____

Address _____

City,St,Zip _____

Phone # _____

Email _____

May we have your permission to contact your veterinarians to request records and discuss your dog's health history, diagnostic testing, and possible treatment options? Yes No

Signed: _____ date: _____

Behavior and Activity survey follows – please complete for all sampled dogs

CHANGES IN BEHAVIOR

Compare this dog's current behavior to its earlier behavior. Please circle the correct answer.

If you need additional space to describe changes, please use back of form or attach additional pages.

	Normal - or - Degree of Change				Describe Changes & Age of Onset
1. Housetraining	normal	mild	moderate	severe	_____
2. Interest in food (eating habits)	normal	mild	moderate	severe	_____
3. Appears nervous	normal	mild	moderate	severe	_____
4. Interaction/socialization with other dogs	normal	mild	moderate	severe	_____
5. Aggressiveness to other dogs	normal	mild	moderate	severe	_____
6. Aggressiveness to people	normal	mild	moderate	severe	_____
7. Tolerance to grooming or bathing	normal	mild	moderate	severe	_____
8. Tolerance to being alone	normal	mild	moderate	severe	_____
9. Ability to recognize/respond to commands	normal	mild	moderate	severe	_____
10. Ability to recognize or respond to name	normal	mild	moderate	severe	_____
11. Recognizes you or other familiar people	normal	mild	moderate	severe	_____
13. Responses to noise/loud sounds	normal	mild	moderate	severe	_____
14. Development of compulsive behavior	normal	mild	moderate	severe	_____
15. Circling	normal	mild	moderate	severe	_____
16. Wakes you more at night	normal	mild	moderate	severe	_____
17. Inappropriate or persistent vocalization	normal	mild	moderate	severe	_____

CHANGES IN PHYSICAL ACTIVITY

Compare this dog's current physical activity to its earlier activity and ability. Please circle the correct answer. If you need additional space to describe changes, please use back of form or attach additional pages.

	Normal - or - Degree of Change				Describe Changes & Age of Onset
18. Climbing up or down stairs	normal	mild	moderate	severe	_____
19. Tremors or shaking	normal	mild	moderate	severe	_____
20. Seizures	normal	mild	moderate	severe	_____
21. Increased stiffness or weakness	normal	mild	moderate	severe	_____
22. Difficulty in movement or coordination	normal	mild	moderate	severe	_____
23. Changes in posture ("roached" back)	normal	mild	moderate	severe	_____
24. Tail carriage when alert & interested	normal	mild	moderate	severe	_____
25. Ability to see during the day	normal	mild	moderate	severe	_____
26. Ability to see at night in dim light	normal	mild	moderate	severe	_____
27. Head movements	normal	mild	moderate	severe	_____
28. Trance-like behavior	normal	mild	moderate	severe	_____
29. Bumps into objects, clumsy	normal	mild	moderate	severe	_____

Please describe any other health problems or behavioral abnormalities:
