

Flash!!!



Flash!!!



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To all Members and Ships at Sea!!!

The Board of Directors of The Pekingese Club of America, and I, are proud to announce that we have joined the Genetics Branch of the National Institutes of Health in the first clinical investigation and study of the inherited characteristics of the Pekingese breed known as its genome.

It is during this 100th birthday year of our club, during its birthday month of May (1909), that we have been able to initiate a basic study of Pekingese canine inheritance, their methods and their possible improvements, by our national laboratories.

We have come a long way and more is now expected.

With all best wishes for the future of our club and the breed, I remain

Sincerely yours,

Gabriel A. Covo

Gabriel A. Covo, M.D.



Cancer Genetics Branch, NHGRI, NIH
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May 18, 2009

Dear Members of the Pekingese Club of America Health Committee,

The Ostrander Laboratory of the National Human Genome Research Institute is proposing a new, exploratory genetic study focused on Pekingese health. You will find a full description of this study following this letter. In short, we would like to collect blood samples and health information from a small cohort of Pekingese of healthy and "affected" status. Affected dogs of interest are those expertly diagnosed with aspects of brachycephalic airway syndrome (BAS). Upon collection of sufficient number of samples from healthy and affected dogs, we will then follow with full genome scans for association with BAS. At the same time we would like to collect morphological data (i.e. body measurements such as height at the shoulders or width of the chest, coat type, variation in coloring, etc.). These data can be used to help find the genes that are involved in body development, such as skeletal growth, and allow us to get an abundance of information from a single collection.

We will collect blood samples from dogs greater than one year of age, for inclusion in the study. In addition, we will happily work with any researchers with which the club has current collaborations to make sure that the samples are used to their fullest potential, to the betterment of Pekingese health.

Please take our proposal into careful consideration as we are suggesting a collaboration that requires a commitment from both of our organizations in order to see it through. We are very excited about the prospects of this study and look forward to working with the Pekingese Club of America for many fruitful years to come.

Sincerely,

Jeffrey J. Schoenebeck
PRAT Postdoctoral Fellow
Cancer Genetic Branch
National Human Genome Research Institute
National Institutes of Health



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The Pekingese Brachycephalic Syndrome Pilot Study

The Ostrander Laboratory of the National Human Genome Research Institute, at the National Institutes of Health (NIH), would like to enlist the support of the Pekingese Club of America and Pekingese fanciers nationwide, to begin a pilot study aimed at understanding the genetics of brachycephalic airway syndrome (BAS). Our aim is to use a combination of blood samples, physical measurements, and health information to examine health issues important in the breed. We will then generate genetic data in an effort to find gene(s) important in BAS disease susceptibility and progression.

Pilot Health Study Participation

Dogs suffering from BAS display a number of breathing abnormalities related to aberrant tissue growth and distortion of breathing airways. BAS abnormalities may include any combination of the following: stenotic nares, elongated soft palate, everted laryngeal sacculles, restricted tracheal diameter, and tilted dorsal turbinate bones. To begin addressing the genetic of this syndrome, we will focus our efforts on mapping the genetic underpinnings of stenotic nares and elongated soft palate since these conditions are most easily diagnosed with currently available methods.

This study will require a commitment from the owners who enroll their dogs. Since it is unknown whether stenotic nares and elongated soft palate are caused by the same underlying genetics, we will design a pilot study that investigates the two conditions independently. We are aiming to collect blood samples and isolate DNA from ~150 dogs: ~50 healthy, ~50 diagnosed with stenotic nares, and ~50 with elongated soft palates. At enrollment, these dogs should be older than one year in age. While the Ostrander lab will cover the cost of DNA extraction and storage, and all of the molecular biology experiments, we will not be able to reimburse owners for travel to events, veterinary bills related to the blood draw, or shipment of blood samples. We will provide blood-drawing supplies (tubes, mailers, alcohol wipes, syringes, etc.) for group draws done at specialties and will send kits to owners for collection by private veterinarians. In addition to a blood sample, we ask that owners provide the name and sex of the dog, AKC or other registration number, owner

contact information, and a signed consent form for use of the blood in our studies. A sample copy of the consent form is appended at the end of this document. We will also request copies of veterinary reports showing any diagnoses that are made related to BAS, as well as scanned copies of skull radiographs, if available.

All genetic and contact information collected for each dog will remain confidential. Specifically, an owner's participation in the study, their dog's pedigree, all health information provided, and genotype data from a dog's DNA sample will not be disclosed to any owners or breeders, Club personnel, the AKC, or the AKC Canine Health Foundation. If owners wish us to provide DNA samples from their dogs to other researchers working on other health problems, in order to avoid multiple blood draws to their animal, we are happy to do so.

Conclusion of the Pilot Study

After scanning the initial 50 healthy and 100 affected dogs, we will consult with the PCA to determine if additional blood sample collections are warranted. If the initial pilot study fails to identify a genetic signal associated with BAS, it could be because the condition is a complex trait (i.e. caused by multiple genes). In such a case, additional samples from both affected and unaffected dogs will be needed to genotype and analyze, to achieve sufficient statistical power, in the hopes of identifying a genetic signal associated with the syndrome.

Alternatively, if the initial pilot study identifies a signal associated with BAS, more dog samples will again be needed, but this time to conduct fine mapping studies aimed at identifying the causal mutation(s) responsible for the syndrome. Results stemming from our fine mapping studies will be published, thus allowing other investigators to develop genetic tests to identify carriers of the deleterious genetic variants. However, our own lab does not develop the specific test, nor do we offer any specific genetic tests.

Our work would not be possible without the participation of responsive owners and enthusiastic clubs. We are sincerely looking forward to working with the Pekingese Club of America on this auspicious project and hope that you feel the same.

Sincerely,

Jeffrey Schoenebeck, PhD
PRAT Postdoctoral Fellow
Ostrander Canine Genomics Lab
CGB/NHGRI/NIH

About The Ostrander Lab

- The Ostrander lab has been a leader in the field of canine genetics since its inception over 15 years ago. We built the first linkage map of the dog and completed at least five iterations that have brought us to a map over 4,500 markers. Our lab has published more than 120 papers on canine genetics and wrote the white paper that resulted in the multi-million dollar canine genome sequence completed in 2005. We currently have active projects focused on finding genes for several types of cancer, hip dysplasia, Addison's disease, osteoarthritis, and a variety of complex physical traits. Finally, we are interested in understanding the architecture of the canine genome and the historical relationships between breeds.



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May 19, 2009

Ladies and Gentlemen:

Welcome to the next hundred years of care and support for the Pekingese breed!
Here is an offer you cannot refuse: let us try to improve the physical health of our, and future Pokes, and, perhaps with celestial guidance, eventually improve our own health too.

In order to begin the long trip to the Wizard of Oz and his colleagues at the National Institutes of Health, I am herewith outlining a syllabus to be followed by owners and veterinarians, alike. Please keep this information, for the present, as it may require amendments and alterations as may become necessary, along the way.

1. The NIH will provide cylindrical kits with a screw-top, made of sturdy cardboard, 6 ½ in. high and 2 ½ in. wide. In it is a metal cylinder, also with a screw-top, that contains two (2) protectively-wrapped glass vials that are vacuumed, stoppered and contain liquid anticoagulant. Within the cardboard container, you will also find two (2) printed forms: (1) an instruction sheet and (2) a consent form for blood donation, plus a return self-adhesive label to Donna Viglietti, the collection agent at NIH.
2. Have your vet collect two (2) tubes of venous blood (required for a total accurate study of the genetic information) from each dog, mix each gently with the anticoagulant liquid, label appropriately, seal and re-pack the tubes into the metal cylinder, and re-cap securely. Insert the metal cylinder, with the two forms completely filled out, plus a 3-generation pedigree (copy) into the outer cardboard cylinder, re-cap securely (may need an adhesive tape around the outer cap), apply the enclosed label, and mail to NIH. A carrier (FedEx, United Parcel Service or the like) may be best, to track and avoid loss of the valuable package. [See below]

Over, please →

3. To complete the picture, in the future, we may need:
 - a) X-ray views of the skull: antero-posterior, if possible, and lateral views.
 - b) If your dog has ever had a back problem (the “back out of whack” syndrome), please have lateral films of its spine, as well. If the vet finds that other views may be necessary, please have him (or her) take the appropriate views, too.

4. All material is considered “privileged” and private, known only to the NIH technicians and the owners of the dogs. No one else will have access to this information.

At present, rather than flood the NIH laboratory with questions and problems, please send them to me, preferably by **fax or surface mail** on your letterhead, so that I can keep a hard copy for future reference. If I can, I will answer the questions. If I cannot, I will relay them to the appropriate NIH office, and send you the correct answer.

The NIH has offered to set-up tables or booths at show sites for collection of the necessary bloods, histories and other paper work, at no charge. Collections would probably be best after the show so as not to interfere with the dogs’ attention and to avoid any disturbance by the minor procedures. They will provide the kits (above) and all paper work can be completed then and there. Copies of the dog’s AKC registration (with number, etc.), its 3-generation pedigree and a brief history of problems, should be brought with the dogs. Dr. Udenberg has offered his services at those sites to evaluate the dogs and help collect the bloods required. Other vets may be available for those services throughout the country. Details to follow as we receive them and arrange for them.

This is a huge undertaking, a most valuable one, and one that will take time to properly evaluate to consider options for repair and improvement. Please be patient and help us all find “the Wizard!”

Enough, for now,

Gabe



Consent for Blood Sample Donation

Canine Genome Project • Ostrander Lab • National Institutes of Health

Research Statement:

We would like to obtain a sample of whole blood from your dog. The blood extraction is to be done by a licensed veterinarian or a veterinary technician experienced in canine phlebotomy. DNA extracted from the blood sample will help us better understand genetic issues related to canine health, including disease susceptibility, morphology and patterns of genetic diversity between breeds.

What are the risks involved with obtaining a blood sample?

Blood is extracted with a needle, typically from a vein in the foreleg, using standard sterile technique. The risks involved are minimal. They include slight pain or discomfort during the draw, a bruise caused by minor seeping or blood around the puncture and a small amount of blood loss. The chance of excessive blood loss is rare. NIH and its employees will not be liable for any damage or injury sustained by any person or persons or property as a result of the blood draw process. Compensation is not available in the unlikely event of physical harm to your dog resulting from the blood draw procedure.

Who will have access to the information and specimen?

Only the Ostrander lab staff and their direct collaborators will have access to the information you provide and the DNA sample from your dog. No information or DNA will be shared with other members of your breed club or the AKC and its agents, unless and when you approve so in writing. Your dog will be identified in public talks and published studies only by a unique Ostrander lab study ID number. Your dog's pedigree and AKC number, as well as your own contact information will be kept strictly confidential. It is understood that you will receive no individual results regarding your dog, no unused DNA will be returned to you, and that study participants have no claim on intellectual property or patents resulting from the use of your dog's DNA sample.

Dog Owner's Statement:

I have read the information provided above and have had an opportunity to ask questions regarding the procedures involved. I am the owner or the agent for the owner of the dog described below and I have the authority to execute this release. My signature below indicates I voluntarily agree to give my dog's blood sample for this study.

Owner's Signature _____

Date _____

Please Print Your Name _____

Email Address _____

Phone _____

Street Address _____

City _____ State _____ Zip _____

Dog's Registered Name _____ Dog's Call Name _____

Dog's Breed _____ Male Female

Registration Number _____ Date of Birth _____

Please remember to include a 3 generation pedigree. Thank you!