

Proposed World-Wide Leonberger DNA Archive - report to the 2014 ILU Delegates' Meeting

Introduction to the concept.

Over the past 10 years or so, there have been a number of ad hoc Leonberger DNA collection drives by various institutions for various genetic studies around the world. Some of these collections have been retained, and up to date health details on the individual Leos has been sought from owners. Many others however were not retained, and the samples have become lost or the samples became increasingly meaningless over time because of lack of information about the ongoing health status of the dogs as they aged. At the International Leonberger Union delegates' meeting in September 2013, the ILU health committee proposed an idea to create a world-wide Leonberger DNA collection and storage scheme that would gather samples and associated health records together into one collection, in order to facilitate future genetic research for the benefit of our breed.

The ability to have DNA from a specific breed held in one collection, with a standardised collection and sample gathering protocol, alongside a comprehensive pedigree database, linked to an up-to-date method to collect and match verifiable health information for each dog sampled- throughout its life- is the "gold standard" for a genetic population study group. As far as we are aware, there is no other comparable example of such a scheme in any other breed. What this will mean is that when new research initiatives are being planned, our breed will be ideally positioned to become the population that is chosen for the study and that therefore, we are likely to be well positioned to get the benefit of any positive outcome from any such research. We have recently seen the beginning of a promising new trend to share collections from one research project to another. Specifically, there has been a sharing of samples gathered for neurological research with another previously unrelated study focusing on osteosarcoma. In a sense this has served as a "proof of concept" for the broader ILU proposal.

It was proposed that we take a year to do a feasibility study to explore the practicalities of trying to establish such a project. At that time, a set of questions was posed, and these have formed the basis of our efforts over the past 12 months. We are pleased to report now that not only is it a realistic possibility, but also that there is a team of highly regarded international centres of excellence in canine genetics that are eager to partner the ILU in such an undertaking.

Feasibility.

On September 4th, a conference call was held which included representatives from the Department of Veterinary Biomedical Sciences at the University of Minnesota, The Institute of Genetics in Berne Switzerland, the department of Canine Genetics at the Animal Health Trust in Britain, and with the Leonberger Health Foundation in the United States. The purpose of the discussion was to bring back some specific answers to the basic questions that we set for ourselves last year when we began to explore this idea. They are:

1- Can we find appropriate facilities to bank DNA samples from Leonbergers, and what will be the logistics and potential costs – if any - of this service?

It was agreed that the partners assembled for the meeting represented a good coalition for this proposed project. All are keen to be involved, they are willing and able to handle, log, store, process and transfer genetic materials between themselves, and they also have a history of successfully collaborating together on previous projects. Physical samples would be stored by any one of the three partner institutions, rather than shipped to one specific location for storage. It would therefore be a single collection, housed in three locations internationally, but held together under a jointly administered database and management scheme.

2- Will we (The ILU) be able to control these samples and to have a role in determining how and by whom they are used in the future? This will include safeguarding the confidentiality of individual dogs so that breeders will feel no threat in cooperating.

It is proposed that a committee of the collaborating partners, as represented in the initial conference call, would be sufficient to consider any approach for future research access to the collection. It is understood from the outset that any such proposed project must be based on sound science first and foremost. It was agreed that the ILU shall always have a representative in this project selection committee and that owner confidentiality will always be respected. It was also agreed that no access to the collection would be granted that did not benefit the breed directly or indirectly, (such as to unrelated commercial studies for the cosmetics industry for example). The committee will be mindful of the health issues that affect the breed and will favour sound proposals that touch upon these conditions.

It is understood that the database portion of the project will be developed with funding from the Leonberger Health Foundation under the auspices of the International Leonberger Union, which represents the owners and breeders, and that it is under the umbrella of the ILU's authority that this crucial portion of the DNA archive project will reside.

The current administrative burden in managing present sample collection is not big- the largest cost is the time needed to individually contact owners. If this were to be at least partially automated through the development of the new owner-updated database, it would vastly improve things. Administration costs would therefore likely not be prohibitive for this proposed scheme.

Partner institutions will be asked to propose an annual administrative fee for their portion of the project's running costs, and we will then look at how to finance the aggregate cost, such as through LHF grants as well as donation gathered at club events, etc. The LHF would establish a sub-fund to handle this. It is understood that trickle funding from the club events is likely, but not guaranteed. Owners will be asked for donations, and clubs will also be asked to seek donations when they do sample gathering events, etc. Furthermore, the LHF has offered in the past to assist in covering administration costs for Minnesota, and would be willing to do so in future. Future research projects utilising the collection may also be asked to provide some support through their own budgets.

3- Can we find a way to encourage the sharing of current collections of DNA from Leonbergers that are already stored by various research programmes and make them also available for future research collaborations?

Other DNA collection drives for our breed are known to have occurred and we have information on collections in countries such as Finland, France the Netherlands and in the United States. It was agreed that there is no harm in approaching the institutions holding these samples, once the Leonberger project is underway, to invite them to add their collections to it. We would not however be seeking to broaden the actual circle of partner institutions managing the future Leonberger bio-bank. The three currently proposed are thought to be enough.

4- How can we ensure that the health status of dogs from whom samples exist is kept up to date?

The LHF has now established a fund (in memory of Waltraut Zieher) to finance the development of an owner-updatable health database. This would include the ability to enhance the information submitted with the inclusion of- for example- veterinary reports, to add further verifiable detail.

The World-Wide Independent Leonberger pedigree database has been offered to be bundled into this future health database. This means that not only would we have a full pedigree database, we'd have current and verifiable health status on participating Leonbergers as well as stored DNA samples corresponding to those dogs. This would equate to the most scientifically attractive DNA research collection that could be achieved.

5- Can we develop a standardised DNA and health survey collection and handling system that all member clubs can then use as a model in their own countries?

As part of this proposed scheme, we will develop a standardised sample collection protocol, so that leonberger clubs, veterinarians and individual owners will all have a simple and clear method for submitting samples. Currently, even when the owner is willing and able, it is not always clear or simple to determine who

to send a sample to, what form they should take and how to handle them. This means that the vast majority of collection opportunities are simply lost.

We propose to have a one-stop-shop in the form of three collection hubs, with identical collection and reporting procedures, available in multiple languages, that any group or individual can easily access and submit to. They would in reality be three branches of the same pooled cooperative effort, and would therefore all share the common database to manage and maintain this collection. Automated update requests would then be sent out annually to owners asking for information on the health of their individual Leonbergers.

Conclusion.

In conclusion, we feel greatly encouraged by the response thus far to this proposed scheme, and are thankful for the initial enthusiastic support that our proposed partner institutions have shown for it. Furthermore we are incredibly grateful to the Leonberger Health Foundation for so generously offering to step up and cover the design and development costs for the creation of the associated health database that will form such a vital part of the scheme, as well as for offering assistance with the basic administration expenses. Lastly we appreciate the very generous offer by the World-Wide Leonberger Database to provide the bedrock pedigree database upon which to build such a scheme.

It is understood by all that the details presented here represent a preliminary proposal, and that no organisation, individual or institution has as yet formally agreed to anything. Our hope is to set everything in place so that we might launch the proposed World-wide Leonberger DNA archive in 2015.

We formally recommend this proposed project to the ILU.

ILU Health Committee, September, 2014