

2015 Report from the ILU Health Group:

1- Research updates;

As many ILU members will be aware, there is a major international osteosarcoma study involving teams in the USA, Sweden and Britain, which we are supporting. The aim is to identify the genetic risk factors for osteosarcoma in breeds such as the Leonbergers. 1 in 4 dogs regardless of their breed, will develop some form of cancer in their lifetimes. It is the number one cause of death in all dogs over the age of 2. As with all cancers, (of which there are over 200 known forms), osteosarcoma is a disease of the DNA. It is triggered by damaging alteration to the genes. Whether this is caused by environmental agents, radiation damage or through random mutation arising from a cell replication error, when the DNA of a cell is altered, this abnormality can lead to unchecked replication, which is in essence what all cancer is. When a breed such as the Leonberger shows a significantly higher rate of a certain type of cancer- far above the all-breed average- it is assumed to have a genetic predisposition for this type of cancer. In Leonbergers, this is certainly the case with osteosarcoma, where the incidences are far higher than in the general dog population. It is important to understand that a genetic predisposition does not necessarily mean that the dog carries cancer causing genes. It simply means that there is a greater vulnerability to developing a certain form of cancer, and it is almost certain that other factors will play a part in triggering it, such as environmental agents, radiation damage or random mutation.

I recently had an opportunity to speak with Dr Mike Starkey, head of oncology research at the UK based Animal Health Trust and a partner in the international osteosarcoma study being led by the Broad Institute. He provided the following update:

The study is blessed with an abundance of donated DNA samples, both from affected dogs, as well as from elderly cancer-free Leos. They also have a large number of actual tissue samples that have been kindly donated by owners internationally. These samples have been provided in large part through cooperation with the teams at Bern and Minnesota, who have compiled a large Leonberger DNA collection for their LPN studies, which provides 'proof of concept' for the proposed ILU DNA bank project. So, they have more than enough samples to investigate. Progress has unfortunately come to a halt due to the fact that the principal researcher is currently suffering from ill health, and has been for most of the last year. It is hoped that this will clear up soon and that real progress can be achieved in 2016.

We have also received a research update on LPN and LEMP research, which is attached to this report.

2- Video Project;

The video project is well underway. The subject of the project is "Preserving the Genetic Diversity of the Leonberger" and the presenter is highly regarded population geneticist and conservationist Dr Pieter Oliehoek, from the Netherlands. The program separates the subject into several sections: The Founders of the breed; the decline of genetic diversity, the rise of inbreeding, the detrimental

effects of declining genetic diversity, and finally, approaches that can be taken to slow or even reverse this serious decline in genetic diversity.

This past summer, an initial batch of video material was recorded and an initial rough-cut has now been completed. There is still a need to prepare and record further material to cut into a final product, the estimated complete running time of which will be in the region of 40 minutes. Then two additional versions subtitled in German and French will be created, and the completed programs will be made available through a link on the ILU website.

3- International pedigree database;

Our breed is blessed by having an almost complete pedigree database stretching back to the original founders of the Leonberger. The World-wide International Pedigree Database is a fabulous resource; it is publically accessible, robustly searchable, regularly updated and extremely accurate in its information. What is in the public domain is there by the good graces of Wilma Kroon and her team of helpers. But in order to keep it accurate and up to date, there is an immense and unending data gathering, collation, fact-checking and data entry task required. Imagine it as something like an engineer who must constantly feed the furnace in order to keep the train rolling forward down the tracks. Only in this case, the fuel is not spent; instead it is painstakingly constructed into an ever bigger puzzle. The value of this database is entirely dependent on its factual accuracy, it is only as good as the reliability of the information that is constantly being fed into it.

This is clearly a huge administrative task, and the ILU should now perhaps have an open discussion about whether or not our breed can afford to rely on the generosity of willing volunteers to keep it running, or indeed should now consider whether there isn't a shared responsibility to support this immensely important work, including the financial burden of maintaining this vital resource for the breed.

Wilma Kroon has compiled a summary document, which is attached to this report, (appendix 1) which details the current sources, country by country, for acquiring accurate registration details for new litters, which are the vital building blocks of this database. The ILU health group now suggests that each member club should determine how they can do their part in helping to keep this valuable shared resource functioning, by selecting a person to collect and forward their own regions' annual registration details to Wilma and her team.

4- Update on the DNA bank project;

The proposed DNA bio-bank project is making slow progress. Our proposed research partner institutions remain committed to the concept of helping to achieve the goal of gathering and maintaining a unique DNA resource for the breed, to enable future health related studies. Again, the recent collaboration with the osteosarcoma study provides ample evidence of the potential value of such a DNA archive.

There have been some set-backs over the last year relating the development of the proposed health-status database that is designed to provide a means to gather and maintain up-to-date details of the health and lifespan of all Leonbergers from whom DNA has been gathered. An initial plan to pursue this development through collaboration with a separate database project currently being funded by the Leonberger Health Foundation broke down due to communication issues and questions about methods, development strategies and confidentiality requirements.

Ben Kroon and Metha Stramer are working now on a try out model.

The Independent Leonberger Database will supply a Research Database consisting of common fields like name, Identification, DOB, DOD, Sire, Dam etc.

This Database will be completed with special fields, subject to further consultations with the research teams.

Each team will receive a special access code so they can enter special information on the dogs that will be only available to their team.

Periodical there will be an update on the dogs. A special form has still to be designed and will be done in cooperation with the research teams.

The Ilu Health Committee will assist on demand.

Just to make sure, all information is confidential and is only accessible to the research team in question.

5- Thoughts on the future structure and operation of the ILU Health Group.

The present ILU health group was formed during the delegates' meeting in 2012, following a lively discussion. As we now approach our 4th year, I personally feel that it is time to once more discuss the health group in order to provide a more considered framework for its future operations.

I am aware that within some Leonberger clubs, all sub-committees are appointed and dismissed by the board or main committee itself, without any input from the members whatsoever. In other countries however, all sub-committee membership is determined by precisely the same method as is the main committee; i.e. individuals are nominated and voted on by the membership. Furthermore, there are clear term limits in place, so that no one, least of all any members of the sub-committees, can assume that they have a "job for life" should they wish to have one. I for one favour a more transparent and participatory strategy and therefore now invite the delegates to discuss their views on the following questions:

Should the national Leonberger clubs be invited to propose future members for the health sub-committee?

Should the delegates have the right to vote for who they'd like to see on this sub-committee, as they do with the board itself? Or are you all happy for the board to form and dissolve this sub-committee, independently of the clubs' direct participation?

How many people should be on this sub-committee?

Should there be a term limit, beyond which anyone should need to be re-selected to the sub-committee?

Should these terms be tied to the election cycle of the main board?

Sharon Springel

On behalf of the ILU health sub-committee-

Teresa Schlaffer, Anita Treichler, Wilma Kroon and Metha Stramer

September 14th, 2015

Appendix 1

Pedigree database registration data collection:

Below you see a table with how the data in the Independent Leonberger database is collected and verified. The co-workers of Norway and Ireland send the data in an excel file, which can be imported into the database program directly, The data from the online studbooks needs to be typed into the database program ,data from published studbooks in club magazine or sent directly from the clubs to me also still needs to be typed and so does the data sent by email . This is a very time consuming task and takes about, on average, 4 hours per day.

It would already be a very big help if clubs would send a regular update of the newborn puppies by sending copies of kennelclub registration or even from leonbergerclub administration, but ideal would in an Excel file!

Registered name	sex	Date of birth	Registration number	Chip/tattoo	Sire	Dam	kennel	breeder
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Also appreciated is a regular update of health test results (ONLY official verified tests) HD/ED/Eye/thyroid/LPN1&2/Cardiac/Thyroid/other)

Note: of LPN tests and DNA registration we also need a copy

All above data will also be shared with the researchers database “Leonome”

Country	Pedigrees/litters	Controle/ verification	healthtests	Controle/ verification tests
General	Litters are sent by breeders in emails or by using our Litter form. Individual dogs are also sent to us this way by owners	Online studbooks, studbooks sent by clubs Copy of pedigrees Website breeder	Clubwebsites Email Studbooks On pedigrees	Copy of health test Test result mentioned in studbooks & on pedigrees.
Australia	ileodata	Breeders/owner	ileodata	
Austria	clubwebsite		Clubwebsite & pedigrees	Copy & pedigrees
Belgium	clubwebsite	studbook	Clubwebsite	stdb&peds
Canada	2 clubwebsites	Studbook sent by club		stdb&peds

USA	Clubwebsite	If I have 1 reg number I can look up the registered siblings one by one on the AKC website	OFA site	OFA site
Czech Republic	2 clubwebsites	Online studbook Admin club	Clubwebsite	stdb&ped
Denmark	Coworker database & clubwebsite		Clubwebsite	stdb&ped
Estonia	clubwebsite		Clubwebsite	stdb&ped
Finland	clubwebsite	Studbook online	Studbook online	Studbook online
France	Clubwebsite & www.chiots-de-france.com	Studbook published by club		stdb&ped
Germany	clubwebsite	Studbook	Clubsite	Studbook
Hungary	clubwebsite	Admin club		
Ireland	Coworker database	clubwebsite		
Italy	2 clubwebsites	Studbook online	Studbook online	Studbook online
Latvia	2 clubwebsites			
Lithuania	clubwebsite			
Netherlands	Clubwebsite studbook	Studbook Directly from KC	Data directly from KC Coworker database club)	Data directly from KC
New Zealand	clubwebsite	ileodata	clubwebsite	ileodata
Norway	Coworker database & clubwebsite	studbook	Norwegian	

			Coworker database(boar d club)	
Poland	Facebook websites	No club/no studbooks online therefore emails to breeders		
Rep. of Serbia		No club/no studbooks online therefore emails to breeders		
Romania		No club/no studbooks online therefore emails to breeders		
Russia	clubwebsite		clubwebsite	
Slovak Rep.	clubwebsite		clubwebsite	
South Africa		No club/no studbooks online therefore emails to breeders		
Spain	clubwebsite			
Sweden	clubwebsite	Online studbook	Studbook online	Studbook online
Switzerland	clubwebsite	studbook		
UK	clubwebsite	Online U.K. leonberger studbook		Online U.K. leonberger studbook