

Minutes of the International Leonberger Union Health Committee Meeting

A meeting of the International Leonberger Union (ILU) Health Committee was held via Skype™ at 14:15 GMT, on 8 May, 2013. In attendance were Health Committee members: Wilma Kroon, Teresa Schläffer, Sharon Springel, Metha Stramer and Anita Treichler. Others in attendance: Hein Sibrijns.

Introduction of the ILU Health Committee to Member Countries

Sharon discussed timing of sending the introduction letter to member countries. Hein was consulted as to whether the Committee needed ILU Board approval before sending the letter of introduction. Hein advised the Committee was independent of the Board and, in his opinion, did not need Board approval to correspond with member countries.

Anita asked if she should send out the German version, Metha send out the French version and Sharon send out the English version of the letter. By consensus, it was decided Sharon would send out all 3 translations to all member countries at once. Responses sent to Sharon will be forwarded to the Committee, and responses, if needed, will be translated back to English by Anita (German) and Metha (French).

Questionnaire from Universität Bern

Anita informed the Committee the researchers at Bern will be sending a questionnaire to all Leonberger owners that have sent DNA samples for the Leonberger Polyneuropathy 1 (LPN1) testing. The questionnaire will have 3 sections: section 1 asking for updated information on LPN; section 2 asking for information on cancers in the Leonberger; and section 3 asking for general information. The questionnaire will be used to assist not only the continued research at Bern, but will also be used to determine if information and DNA samples can be shared with the researchers at Uppsala Universitet in Sweden (and the Broad Institute in the United States) for the Leonberger osteosarcoma research.

Teresa asked if the same questionnaire would be mailed to the LPN study participants from the University of Minnesota. Anita did not believe so, but was unsure. Teresa said she will contact the University of Minnesota to confirm.

Discussion ensued about other studies in Europe with similar data and DNA samples available, and if the owners of those participants should also be contacted. Anita will check with the researchers at Bern to determine if additional study participants would be needed. Teresa will consult with Dr. Linblad-Toh to see if additional study participants need to be identified in the US for the osteosarcoma study.

Teresa mentioned additional funding would be needed to continue the osteosarcoma study. Sharon mentioned the club in the UK had some funds to send for the research and wondered if matching funds the LHF offered were still available to member clubs. Teresa assured her that

yes, the offer was still available. Teresa will send banking information for donations to the Committee. It was further decided that research funding would be added to the agenda for a future meeting of the committee.

Publication of Health Committee Information

Teresa asked if it would be permitted to provide information about the ILU Health Committee for publication in the Leonberger Club of America's quarterly magazine, the LeoLetter. It was agreed that information disseminated through whatever means available to the Leonberger community should be encouraged. Anita said that she too will write a short article for the magazine published in Switzerland. The members agreed to share any article written about the Committee with other members for adaptation to other publications.

Sharon suggested that the Committee should be as transparent as possible to the Leonberger community. She suggested the committee create minutes of meetings, and make them available to the Leonberger community in general and to the ILU member clubs specifically. Teresa offered to post the minutes on the Leonberger Health Foundation's website. Hein suggested that it should be posted on the ILU website. It was agreed the ILU website was the most appropriate forum.

It was suggested the minutes be written in English and it was agreed that Teresa would draft the minutes for each meeting for approval by the Committee.

Adjournment

The meeting was adjourned at 14:50 GMT and the Skype™ session was terminated.

Respectfully submitted,
Teresa Schlaffer