

BORDER TERRIER BREED HEALTH GROUP

NOTES ON MEETING AT PARK HOTEL, YORK

ON SUNDAY APRIL 9, 2017 AT 10.30 A.M.

Present: Professor Steve Dean (SD) – in the Chair
Dr Andrew Harbottle (AH)
Dr Eddie Houston (EH)
Professor Jeff Sampson (JS)

In Attendance:
Ronnie Irving (RI)

1. **Terms of Reference:** The following terms of reference were agreed for the Group – to be circulated to the seven breed clubs.

To assist the Border Terrier Breed Health Co-ordinator in his task of considering health issues in the breed. These tasks are defined as inter alia:

1. Facilitating the communication and collection of data on the health of the breed.
2. Collaborating with the Kennel Club on any health concerns the breed may have.
3. Acting as a conduit between the Scientists, the Kennel Club and the Breed Clubs.
4. Providing relevant advice and support to owners and breeders through the breed clubs.

2. **Formal Protocols:** Drafts were proposed.

For SPS - Discussion about the variability of the clinical condition and its time of onset raised some concerns about the variability of the phenotype. The pathology reported in the primary paper describes the changes to the myelin as novel and it is possible this is not a single gene defect or that environmental factors as yet unknown might influence the timing of the onset of symptoms. There was general agreement on the importance to discuss this with the neurologists and pathologists as it was critical to understand the condition. The post mortem soon after death or euthanasia would be important to confirm the presence of SLEM in reported cases. It was agreed that formal protocols should be produced for people who think they are encountering either CECS or SPS – to advise on exactly what they and their veterinary surgeons should do so that the maximum amount of accurate information can be gathered from each case.

If puppies do survive or some pups in the litter do not show symptoms of SLEM it will be important for breeders to correctly place KC endorsements to prevent breeding without due consideration of the risk of SLEM in the offspring.

A note for breeders on how to proceed with their breeding plans in the face of the production of an affected litter. In particular those who own dogs that are descendants from dogs identified as carriers will need specific advice.

CECS - Protocol will be similar but a fact sheet on the condition will be needed to help the diagnosis of the condition by the general practitioner before referral to a neurologist. CECS not urgent cases so less need for regional network. Discuss need to see case or if video is sufficient. Important data gathering exercise from local GP and owner. Once confirmed it is important that cases are reported to the BHC along with a pedigree. We need to establish considerable security around diagnosis and the role of the specialist is important. Self diagnosis is unreliable for any pedigree/genetic assessment. DNA samples will need to go with diagnosis to the AHT from the neurologist alongside clinical evidence. Parental DNA will be more challenging to obtain given the age of the dogs when symptoms are first seen.

It was agreed to construct a medical questionnaire for the owners of CECS cases to aid data collection and diagnosis.

The current work (ref Mark Lowrie) attempting to develop a suitable blood test for detecting gluten sensitivity was discussed and its potential for the future diagnosis of cases of CECS.

It was agreed that the draft protocols should be sent to and discussed with the specialists/researchers/geneticists involved in the conditions before final publication.

In the case of SPS it was agreed that because of the need for post mortem work to be carried out promptly, and in order to help breeders to get puppies reasonably easily to the veterinary centre conducting the work, the researching neurologists should be asked to contact and nominate say four or five centres across the UK at which the work could be carried out.

3. **Questionnaire for Owners of CECS Sufferers:** It was agreed that AH should produce a questionnaire for completion by owners of CECS sufferers. This would enable an early and detailed record of symptoms and seizure incidents to be produced for use by the veterinary surgeon, the referral practice and future researchers.
4. **Estimated Prevalence of Conditions:** Reliable and verified statistics on the conditions were hard to come by. SD confirmed that he as Breed Health Co-ordinator had the following for each condition.

CECS – around 25 cases where he had reasonable confidence in the accuracy of the diagnoses and around another 25 where the information available did not give enough confidence in the diagnosis.

It was agreed that SD should contact the RVC to tap into the statistics on the condition from VetCompass the Companion Animal Surveillance System. In the past Vet Compass has reported the Border Terrier as highly associated with

epilepsy but it is not always simple to split seizure cases into CECS, epilepsy or other causes (e.g. brain tumours).

SPS – a number of informally reported/rumoured cases but only three where adequately documented information has been received.

VetCompass could also be asked for SPS prevalence but was unlikely to have much hard data given the small numbers reported. Approaching the veterinary neurologists may prove more helpful.

Prevalence figures would enable a better prioritisation of the illnesses that Border Terriers might suffer and thus direct any research more effectively.

- 5. Pedigree Research:** It was hoped that further pedigree analysis could be conducted on the information to be provided at the afternoon meeting with breeders. At present the data available on SPS is not sufficient to determine the mode of inheritance. Not likely however to be a dominant gene but more data would be required to accurately determine the mode of inheritance.

It was felt that the best way to keep breeders abreast of developments was by creating open registers of dogs which had been confirmed as cases through veterinary diagnosis for the conditions, listing affected dogs and their parents.

In order to obtain maximum 'buy-in' from breeders it was felt that perhaps these registers should start off 'closed' but with permission from the breeders that later the data may be shared openly when enough cases had been accumulated.

JS agreed to be the keeper of those registers and also agreed to draft some words describing the process to be employed so that the breed can work towards an open register for both of the conditions.

Guidance would be needed for dog breeders on how to interpret any information available to avoid an unreasonable reduction in the gene pool. The risks of over reaction is high. Furthermore, the very existence of a breed register for SPS or CECS will raise expectations that good advice can be provided as a result and this is not likely unless extensive, good information is available. However, some useful guidance to breeders with specific lines could be given.

- 6. Meeting with Specialists/Researchers:** It was agreed that the Group should approach the KC Breed Health Department to ask for their help in organising a meeting to obtain up to date information on the conditions and to establish proposed priorities for the future.

Attendees to include:

- Kennel Club Health Department
- Border Terrier Breed Health Group
- Glasgow Vet School (contact: Dr Rodrigo Gutierrez Quintana)

- Liverpool Vet School (contact: Dr Daniel Sanchez-Masian)
- AHT Neurologist
- AHT Geneticist
- Mark Lowrie

It was agreed that SD should start off advising the potential veterinary/scientific participants and RI should contact the KC Health Department to establish possible mechanics of the meeting such as dates, venue etc .

- 7. Animal Health Trust Issues:** RI declared an interest as a Trustee of AHT and SD declared he was Chairman of the KCCT a major funder of the AHT. It was agreed that the BHG should approach the AHT with the suggestion that work on genome sequencing should be accelerated for both CECS and SPS by adding to the programme both a CECS affected case and also a control Border Terrier for use in processing results.

Costs of such acceleration to be established in discussion with AHT. AH felt from his experience that the added work should not be very costly.

SD and RI to contact Cathryn Mellersh at the AHT to arrange a meeting to discuss this and any other key issues.

(Post meeting - In the afternoon session £16k + was confirmed as the sum of money donated to the AHT and not specifically allocated to any particular project)

- 8. Overseas Researchers and Breed Groups:** It was agreed that contact with overseas researchers was best left to the research community itself although the BHG should clearly be kept informed of any international progress.

It was however felt that contact should be made by RI/SD with breed health groups in Scandinavia and the USA so that up to date information can be passed from one group to another and so that members of the UK BHG can be kept up to date on International research.

- 9. Preparing Breeders for emergence of future test:** It was felt that the BHG, in stressing that time horizons for solutions may be quite far off, should also start preparing breeders for the various options that may be put into effect by the Kennel Club and the breed clubs, in the event of the successful development of some screening tests.

RI/SD to approach the KC Health Department (probably Tom Lewis or Katy Evans) to ask if they have any policy literature or guidance on the subject, for adaptation by the BHG and for issue to the breed clubs. We would intend to draw on experience of other breed initiatives.

- 10. Fact Sheets for Owners and the Veterinary Profession:** It was agreed that fact sheets should be prepared by the BHG on the two conditions for use by owners and veterinary surgeons when suspected cases are encountered.

These could be disseminated in various ways including via

- Breed Club Websites
- Various appropriate Facebook Groups
- Veterinary Record and Vet Times etc
- KC System of providing information to new Border Terrier owners.

It was agreed that draft fact sheets should be prepared for CECS by EH and for SPS by SD.

11. Fundraising: It was decided to recommend to Breed Clubs that the setting up of a fund for furthering understanding of SPS and CECS would be helpful and, as far as possible, should leave the deployment of such funds to the BHG and thus the ring-fencing of funds should be avoided as far as possible.

SD and RI to contact clubs accordingly.

12. Relationship with Breed Clubs

It was agreed that communication on the activities of the BHG needed to be distributed as widely as possible. It was also agreed that the Breed Clubs should be asked to be the conduit for spreading as much information as possible to the Border Terrier owning public.

It was also agreed that Breed Clubs should be asked to nominate one person each to attend prearranged meetings with the BHG to be updated on issues and to provide feedback to the BH Group. (RI to progress)

(Afternote: Those who attended the afternoon meeting suggested that such representatives ought perhaps to be asked also to act as a liaison with owners of dogs with the two conditions, and to help counsel them.

They also suggested the development of a specific Border Terrier Health Website that might be used by a wider audience than those who currently consult breed club websites.)

13. Other issues:

On examination of the other conditions listed in the most recent Breed Health Survey, it was felt that the BHG should concentrate its efforts on the two breed specific issues, and meantime leave other work on issues such as Cushing's Disease and Cancers to the wider canine research community.

AH agreed to prepare a summary of Border Terrier health surveys.

14. Afternoon Meeting:

The meeting was Chaired by RI and was attended by all members of the BHG and by Janet Lee, Michelle Barnet, Linda Coleman, Geraldine Cove-Print, Jan Gale and her husband, Stewart McPherson, and Andrew Mooney.

Some of the visiting individuals were at pains to make it clear that they were not part of any 'group'.

The main subjects for discussion were the two conditions CECS and Shaking Puppy Syndrome (SPS). The pedigrees of 19 SPS litters were handed over to the Breed Health Group along with information on various aspects of CECS, these were the pedigrees made available at the recent February meeting organised by Janet Lee.

The meeting recognised the tremendous amount of work that had been put into the issues particularly by Janet Lee, Jan Gale and Michelle Barnett in both assembling information about the conditions and affected dogs, and also in the carrying out fundraising efforts that had so far collected over £16,000 for use by the Animal Health Trust for work on the two conditions.

The main concerns expressed by those present centred around criticism that the Breed Health Co-ordinator had not been responsive enough to those reporting the conditions in the past and not enough had been done by the Breed Health Group to draw attention to and tackle the conditions. There was a lack of trust that matters would be moved forward, and as to whether the Breed Health Co-ordinator and Breed Health Group would get to grips with the issues. Some believed that this lack of trust would mean a reluctance to report issues to the BHG. The Chairman stressed that we should all concentrate on the future rather than the past, and on unity rather than divisiveness. Clearly the BHC and the BHG would have to work on building back that trust, in the interest of the breed.

RI dismissed suggestions that the BHC should be replaced, and he made it clear that the appointments of the BHC and members of the BHG were matters for the breed clubs and not for individuals.

Those present also put forward a number of very positive suggestions for the future including:

- Appointment by each breed club of a liaison person per club to talk to concerned dog owners and provide links between such owners and the BHG.
- Creation of a Breed Health Website
- Use of funds to sequence further cases of SPS and to include genome sequencing of CECS cases.
- Better future communication of BHG meetings, advice and decisions.

The BHG undertook to take these suggestions on board.

The meeting closed at 5.20 p.m.

ACTIONS

SD

- contact RVC to tap into the statistics on conditions from VetCompass
- advise potential veterinary/scientific participants of need for meeting with researchers
- draft fact sheet on SPS

AH

- draft questionnaire for owners of CECS sufferers
- draft summary of BT health surveys.

EH

- draft fact sheet on CECS

JS

- draft words describing the process to be employed so that the breed can work towards an open register for both conditions.

RI

- Contact KC Health Department to establish possible mechanics of the meeting with researchers - such as dates, venue
- ask Breed Clubs to nominate one person each to attend regular meetings

SD/RI

- contact Cathryn Mellersh at AHT to arrange a meeting to discuss sequencing acceleration and any other key issues.
- contact breed health groups in Scandinavia and the USA to share information
- approach the KC Health Department for policy literature or guidance on control schemes
- recommend to Breed Clubs setting up of unrestricted funds for research on the conditions