IPFD 4th International Dog Health Workshop (IDHW): Outline for Participants

General Goals and Outcomes - all Themes:

By the conclusion of the 4th IDHW participants should leave with a clear sense of key decisions on priorities / needs within the theme; remaining gaps/ challenges/ controversies; List of specific tasks/ actions to be undertaken over the next two years, by whom; and a clear understanding of how they, personally, will help achieve the desired outcomes.

Please see: 4th International Dog Health Workshop Pre-meeting Resources including:

- current overview of entire workshop; schedule; speakers list and poster invite, as well as,
- page for each, with links to more resources.

.... Please note this is still evolving... check for new updates until the workshop...

Genetic Testing for Dogs Theme

National and international programs and approaches to studying and improving health of dogs within a breed.

- Working Group Coordinator(s): Aimee Llewellyn-Zaidi, USA;
- **Resource persons**: Dr Clare Wade, AUS; Dr Tom Lewis, UK
- Facilitator: Dr Sue Pearce-Kelling, USA
- Note Taker: TBC

Context for the theme:

In previous Dog Health Workshops, it was recognised that the proliferation of genetic tests and test providers, is a huge concern. There has been increased public and professional interest in the many issues related to genetic testing including the lack of standardisation or regulation for the delivery and application of testing. Many stakeholders – researchers, commercial and academic test providers, the veterinary world, kennel and breed clubs, and other - are involved and all have a role and responsibility to address the challenges if the great potential for genetic testing to improve dog health is to be achieved. The IPFD IDHW is one of few events bringing together those from all stakeholder groups and the main goal is to improve communication, to learn what efforts are underway, and to identify and prioritize needed actions that should go forward collaboratively and/or in parallel.

Identified as a key initiative at the previous IDHW, the IPFD Harmonization of Genetic Testing for Dogs (HGTD) database was launched in Spring 2018, providing an international listing of genetic test providers (GTPs), "quality measures" (QM) and attributes of the GTPs, tests that are available by breed, a 300+ database of canine tests/phenes, and general information resources on accreditation and genetic testing. This initiative can provide transparency and resources to support decision making by owners, breeders, breed clubs, veterinarians, etc. There have been significant challenges in developing this resource, most of which further underline the need for it, e.g.: resistance of some GTPs (both academic and commercial) to provide data, selling of tests to breeds for which the test is not validated, inaccurate/inconsistent use of nomenclature about tests and results that is a source of confusion for consumers, lack of funding for proficiency testing, etc.

Beyond the HGTD many kennel and breed club health committees struggle to make recommendations about genetic testing, and there continue to be limited effective resources and a need for more/more accessible and independent genetic counselling. It became increasingly evident in 2018 that IPFD was a needed, balanced and arms-length voice that could provide a broad view of both issues and ongoing actions. More than ever there are few geneticists worldwide who are not affiliated with commercialized testing. There are some efforts to promote further training for veterinary professionals (e.g. AKC-CHF). Even well-recognized researchers maybe delaying or avoiding peer-reviewed publication of their research, and the situation with un-validated tests being sold widely is perhaps worsening. The preponderance of focus on single gene mutations, the lack of adequate attention to breed-specific differences creates a need for better education on application; the focus on Direct-to-Consumer testing, increased ease of access to panel testing offers both benefits and challenges.

Given these complex and considerable challenges, a main goal the Genetic Testing theme will be to identify and prioritize issues that need focus. Action plans/working groups will be identified with outcomes specified for the next two years.

A short survey will be circulated to those registered for theme to get a head start on this work prior to the meeting. Topics include: HGTD, lab/testing "quality", breed-specific testing/genetic advice, research concerns.

Keys to the Genetic Testing Theme:

- **Maximizing our time** within the time constraints of the workshop, how can we make the most out of this unique multi-stakeholder group to provide a foundation for progress?
- **Prioritizing Development:** What truly matters NOW. With limited resources, what needs to be prioritized for 2019-2021?
 - Presentation and discussion of **pre-meeting survey** results.
 - Selecting and discussing our focus and priorities
 - Setting of SMART goals to move forward with focused, and prioritized development.
- **IPFD and the HGTD:** Building on the successes of the HGTD database, i.e. phene information, QM data, international GTP listings, breed-specific available testing, how do we?
 - Address the challenges for HGTD: financial sustainability, up-to-date data, new project development, spreading the word about this resource to key stakeholders: GTPs, vets, owners, breeders, researchers, breed/kennel clubs, etc.
 - Continue to engage further sponsors, collaborators, and Experts to address the challenges of: describing "quality" GTPs, describing "quality" genetic tests, and genetic counselling/advice
 - Expert Panel development IPFD has the infrastructure to build a collective resource.
 This will be presented at the workshop. What will be the keys to making this a success?
 - Genetic advice: how does this fit within the bigger picture health counselling?
 Developing a Health Strategies Database for Dogs (see below)?

Possible Questions for the Breakout Sessions – to be refined based on pre-workshop survey.

- Given that 'genetic testing' covers a wide range of applications, e.g. disease testing, heritage/breed composition, parentage, diagnostic, etc., and that the market is mainly Direct-toconsumer (DTC) – how does that impact 'robust and quality genetic testing'?
- What tools are needed for consumers; are there urgent priorities to address; or a balance to be met across the whole picture?
- How prevalent and impactful are inadequate quality assurance for general laboratory procedures, test-specific procedures etc. relative to other concerns about genetic testing? What are possible ways to promote best (better) practices in the continued absence of regulation/oversight? Would self-evaluation be a step forward, possibly using existing tools?
- Will the commercial testing world (academic and commercial) embrace best practices in the performance and report of genetic tests?
- Role of veterinarians and what tools are needed to support vet-owner/breeder communication
- Roles and responsibilities for robust genetic testing across ALL stakeholder groups? E.g., specific roles/responsibilities for researchers?
- Developing Proficiency Testing what are the next steps forward? Resources? Is this still a key priority?
- Potential for improved collaboration across 'pure' research and commercial stakeholders?

Relevant discussions may go on in other themes, for example:

- Collecting accurate information on populations (demography, prevalence, risk, etc.); potential for comparison and collation across various sources of data.
- Breed-specific Health Strategies Theme: Role of DNA testing in supporting health strategies by country x breed x populations? Also, addressing education challenges: test for and preferably prevent every possible disease, impact on other health and welfare challenges (temperament, conformation, genetic diversity, etc.); running off after the DNA 'test of the month'; knee-jerk reactions to storms on Facebook....
- Implementation of the Health Strategies Database for Dogs, on DogWellNet.com, which will allow interactive search for all conditions, not only those for which genetic testing is available.
- Health and Welfare Issues of Exaggerated Conformation: DNA testing resources impacting complex diseases?

Possible Specific Outcomes for the Harmonization of Genetic Testing for Dogs:

- Assign a working group to create guidelines on prioritised topics, such as best practices from test discovery to application, to distribute internationally. Arrange translations in various countries?
- Proficiency Testing Working Group who is doing something similar? Could they support/guide/lead? Identify the resources and people required to make this happen, develop working group and aim for (at least) a trial by 2020.
- Expert Panel Development "Testers", and first tranche of priority questions
- Genetic Advice Education Resources HSDD is one start. Who can provide, categorize, translate?
- How do we engage Kennel/breed clubs, breeders, veterinary scientists, and other stakeholders in using HGTD databases? Are there others who could be involved?

• Sustainability of the Databases: financial support, data accuracy, practical/expertise support

Organisation of Breakout Session:

Preliminary Time frame

- o Breakouts: 15:00-18:00 on Friday and 8:15-10:45 on Saturday morning.
- Reporting/ sharing from breakouts is from 10:45-12:45 on Saturday.
 - This will include both priorities, gaps and action plans

Focus (tentative) for each Breakout Session:

- 15:00-15:50 Friday
 - Who's in the group and what they would like to achieve; summary of pre-workshop responses (brief survey to registrants).
 - Brief discussion ...
 - Prioritizing issues to address especially those for which we might have actions, for example (e.g. our main priorities):
 - Sustainability and development of HGTD
 - Development and implementation of an Expert Panel, to review and comment on genetic testing issues and developments
 - Development of a proficiency testing scheme
 - International advice on genetic testing within health strategies
 - Laboratory recommended standards/"regulations"
 - Briefing for the next session (i.e. all together or sub-groups, based on priorities?)

• 16:15-18:00 - Friday

- Identifying/prioritizing key challenges that need multi-stakeholder/international cooperation and for which specific actions can be envisioned.
 - These could include education/raising awareness
 - Specific actions on key issues

• 08:15-10:15 – Saturday

- Recapping on Friday's outputs & focusing on actions for the next two years.
- Specifying goals for action items
- Identify working groups to address actions; Assigning people to actions to be completed after 4th IDHW
- Reviewing the outputs
 - Each participant to identify 2-3 practical takeaways to adopt/adapt
 - Agree any gaps/needs
- Preparing a key-point summary to share with participants of other breakout groups
 Preparing the theme presentation to share at 10:45 in plenary

Required pre-workshop activities:

- Return the pre-meeting survey.
- Reading list will be edited according to results of the pre-meeting survey.
- The IPFD and collaborators response to the Nature commentary 'Pet Genomics runs wild'. See: [Genetics and Genomics for Dogs: Balancing daunting challenges and great potential]

Reading and Resources :

- Please make sure you are acquainted with the <u>Harmonization of Genetic Testing for Dogs (HGTD)</u> resources: What do you like, what do you want more of, what is missing?
- <u>Improving Genetic Testing</u> an article on DogWellNet.com describing several recent articles raising concerns about the quality of canine genetic testing. And, in that article, the link to **Standards and guidelines for canine clinical genetic testing laboratories** by Shaffer et al 2018.
- Expert Panel over-view (to be provided)
- First time at IDHW? Check out <u>Moving from information and collaboration to action: report from</u> the 3rd International Dog Health Workshop, Paris in April 2017
- Standards and regulations : <u>ICAR</u>, <u>ISAG</u>
- Direct-to-consumer testing resources : EuroGenTest <u>DTC resource</u>s
- Genetic testing/regulation in the media: HGTD in the Media