

# Participant Information Statement



## *Research Study: Anstee Hub for Inherited Diseases of Animals (AHIDA)*

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### 1. What is this study about?

The Anstee Hub for Inherited Diseases of Animals (AHIDA) is an online platform for surveillance, reporting and facilitating control of inherited diseases in animals in Australia. Veterinarians and animal owners can submit information about inherited diseases and will be linked to information about diseases with similar clinical presentation; available DNA diagnostics; and interested researchers. Researchers can be listed as contacts for future research. Genotyping providers can list available DNA diagnostic tests for specific variants and provide population-based frequency information about variants tested in their facility. Submitting information to AHIDA is voluntary.

Please read this sheet carefully and ask questions about anything that you don't understand or want to know more about.

### 2. Who is running the study?

The study is being carried out by the following researchers:

- Imke Tammen (A. Prof., Sydney School of Veterinary Science, Faculty of Science, The University of Sydney)
- Claire Wade (Prof., School of Life and Environmental Sciences, Faculty of Science, The University of Sydney)
- Bianca Waud (A. Prof., Sydney School of Veterinary Science, Faculty of Science, The University of Sydney)
- Marina Godoy Gimeno (Research affiliate, Sydney School of Veterinary Science Faculty of Science, The University of Sydney)
- Brandon Velie (Lecturer, School of Life and Environmental Sciences, Faculty of Science, The University of Sydney)
- Frank Nicholas (Emer. Prof., Sydney School of Veterinary Science, Faculty of Science, The University of Sydney)
- Brendon O'Rourke (Team Leader Biotechnology, Elizabeth Macarthur Agricultural Institute (EMAI) NSW Department of Primary Industries)

This study is being funded by the Ronald Bruce Anstee bequest to the Sydney School of Veterinary Science

**Conflicts of interest for researchers involved in the project:**

Imke Tammen, Claire Wade, Brandon Velie and Bianca Waud are employed by the University of Sydney and conduct research in relation to the investigation of inherited diseases in animals. The Sydney School of Veterinary Science offers DNA diagnostics for inherited diseases in animals.

Dr. B. O'Rourke is employed as leader of the Genetics Diagnostic Unit in the State Veterinary Diagnostic Laboratory at EMAI, Department of Primary Industries. He is conducting collaborative research with Imke Tammen in relation to the investigation of inherited diseases in livestock and the Genetics Diagnostic Unit is offering DNA diagnostics for inherited diseases in animals.

Members of the AHIDA research team may benefit from being linked to animal owners who submit information about inherited disease as this information may lead to research projects and research funding applications.

Information about inherited diseases in animals gathered by AHIDA may be used by researchers (in a summarised and de-identified manner) for publications and as evidence for funding applications.

### **3. Who can take part in the study?**

We are seeking **animal owners, veterinarians, or representatives of breed societies** in Australia to submit information about animals with suspected or confirmed inherited diseases. We are not collecting information about animals in other countries.

We are seeking **researchers (veterinarians and animal geneticists)** to submit information about their research interests and contact information.

We will invite **genotyping providers** that provide DNA diagnostics for inherited diseases in animals to list available DNA diagnostic tests for specific variants and provide population-based frequency information.

### **4. What will the study involve for me?**

If you decide to take part in this study, and you are an **animal owner, veterinarian, or representative of a breed society**, who wants to submit information about animals with suspected or confirmed inherited diseases, you will be asked to complete a brief online survey in the AHIDA platform (<https://ahida.sydney.edu.au/app/home>). You can provide information anonymously or you can register and provide contact information. You will be asked to provide information about animal details, birth information, death information (if applicable), parentage and disease information, and will be given options about consenting on how we use the information you provide. It should only take 5 to 10 minutes to complete the survey. If you register/provide contact information you can request to be contacted for follow-up regarding clinical and genetic advice or participation in research about the condition.

If you decide to take part in this study, and you are a **researcher (veterinarian or animal geneticist)** who would like to be contacted if animal owners, breeders or veterinarians request follow up genetic counselling or would like to participate in research in your areas of expertise, you can complete a brief online survey in the AHIDA platform (<https://ahida.sydney.edu.au/app/home>) to provide contact information and information about your area of interest. It should take less than 5 min to complete the form. By submitting this information, you consent for the AHIDA team to contact you if animal owners, breeders or veterinarians request follow up in your area of expertise. You can choose at that time to decline or engage with the animal owners, breeders, or veterinarians.

If you decide to take part in this study, and you are a **genotyping provider**, we will ask you to provide a list of available DNA diagnostic tests for inherited conditions and will ask you once a year to provide population-based frequency information about variants tested in your facility. We will provide you with a consent form that outlines additional information.

Some participants may become uncomfortable or upset when providing information about animals with an inherited disease. You may pause or cease participation at any stage. At the end of this form is also a list of services which you may find helpful if you do experience emotional discomfort as a result of your participation.

## 5. Can I withdraw once I've started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind, you can withdraw by contacting the AHIDA team via email: [ahida.admin@sydney.edu.au](mailto:ahida.admin@sydney.edu.au). If you choose to withdraw, we will not collect any more information from you. Please let us know at the time you withdraw what you would like us to do with information we have collected about you or your animals up to that point.

If you submitted information anonymously:

By submitting your survey, you consent to take part in the study. You can withdraw any time before you submit. However, once your responses are submitted, they cannot be withdrawn. This is because they are anonymous, and we will not be able to tell which one is yours.

## 6. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

Animal owners may be concerned about perceived reputational harm disclosing information about inherited conditions in their animals. Animal owners can choose to provide or not provide personal information or information that allows identification of their animals. Personal information of animal owners or information that allows identification of their animals will not be included in reporting or dissemination of AHIDA related information.

Information about animal owners or details about their animals will only be shared with third parties if the animal owner consented to sharing of information.

### Are there any benefits?

If you are an **animal owner, veterinarian, or a representative of a breed society**, your submissions will contribute to:

- improved evidence-based understanding of disease prevalence/incidence, enabling breeders and breed societies to make better-informed decisions on management
- research that enables early intervention via selective breeding based on pedigree analysis or DNA tests, resulting in fewer affected animals being born, for the betterment and welfare of animals

You can directly benefit if you request to be contacted for follow-up (regarding clinical and genetic advice or participation in research about the condition). AHIDA cannot guarantee that detailed genetic counselling will be provided for each submission, and AHIDA is not conducting research into individual diseases – AHIDA just facilitates connecting animal owners, veterinarians, or representatives of breed societies with researchers who have registered with AHIDA.

If you are a **researcher (veterinarian or animal geneticists)**, you may be connected with animal owners, veterinarians, or representatives of breed societies who would like to receive information from you or may want to contribute information or samples to your research.

If you are a participating **genotyping provider**, you will be offered to be named on the AHIDA website. AHIDA will only share detailed contact information of genotyping providers with submitters who report a disease for which a diagnostic DNA test may be available. Submitters will receive contact information for all genotyping providers registered with AHIDA for a specific test. A disclaimer will be provided stating that the submitter needs to check suitability of the test for their animal with the service provider and that AHIDA does not endorse any of the service providers.

## 7. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information about you for the purposes of this study.

Any information you provide us will be stored securely and we will only disclose identifiable information with your permission, unless we are required by law to release

information. We are planning for the study findings to be published. **You or your animals will not be individually identifiable in these publications.**

If you are connected via AHIDA to researchers, who conduct research in a specific inherited animal disease, then this research is independent from AHIDA and should be covered by independent human or animal ethics approval.

## **8. Will I be told the results of the study?**

You have a right to receive feedback about the overall results of this study. Summary information about occurrences of specific diseases in specific populations and/or breeds will be provided via the AHIDA online portal.

If submitters request a follow-up or would like to be connected to researchers or clinicians, we will aim to match submitters with species and disease relevant clinicians / researchers who have provided their contact information to AHIDA

## **9. What if I would like further information?**

When you have read this information, the following researcher/s will be available to discuss it with you further and answer any questions you may have:

- A.Prof Imke Tammen  
Phone: +61 2 935110604 | Email: imke.tammen@sydney.edu.au
- Prof Claire Wade  
Phone: +61 2 9351 8097 | Email: claire.wade@sydney.edu.au

## **10. What if I have a complaint or any concerns?**

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [Project No. 2023/433] according to the *National Statement on Ethical Conduct in Human Research (2007)*.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager  
[human.ethics@sydney.edu.au](mailto:human.ethics@sydney.edu.au)  
+61 2 8627 8176

### **Support services:**

This list is not exhaustive, but may help you to find support services more quickly.

**Lifeline** 13 11 14 <https://www.lifeline.org.au> (online chat/video available 7pm – midnight)

**Mental Health Line (NSW)** 1800 011 511

**Beyond Blue** call a counsellor 1300 22 4636 or <https://www.beyondblue.org.au/>

**Headspace** (for young persons): <https://headspace.org.au/>

***This information sheet is for you to keep***