# **DNA ARCHIVE**



# GLEN OF IMAAL TERRIER CONFERENCE

### ALISON SEALL, UK

FRIDAY 8<sup>TH</sup> AUGUST 2014

HOTEL GUSTAVELUND, TUUSULA, FINLAND

### **DNA ARCHIVE**

- What is the DNA archive?
- Why have a DNA archive?
- Video Sample collection : buccal (cheek) swabs
- Contents of the DNA swab kit
- Submission to the AHT
- Cost to owners
- Health updates & notification of death
- Confidential Glen health database
- Health information
- International archive ...?
- Links & contacts

# WHAT IS THE DNA ARCHIVE?

- The DNA archive is not to be confused with DNA collection for:
  - the Glen DNA test for GPRA-crd3
  - DNA parentage analysis
- The DNA archive offers a storage facility at the Animal Health Trust (AHT) for:
  - Glen buccal (cheek) swabs (or blood samples)\*
  - Pedigree data
  - Health information
- At the time when DNA is required for a research project, the DNA will be extracted and provided to the research team
  - \* N.B. Under UK Home Office regulations a blood sample being drawn solely for the purpose of research must be done so under a very specific license. If blood is being primarily taken for diagnostic purposes then a few mls extra for research would not infringe on the Home Office rules.
  - Blood samples from non-EU countries require an import license reference ~ Please write clearly on the submission envelope: **PATH/11/2009/1**

### WHY HAVE A DNA ARCHIVE?

- Many Glen owners will remember the Bochum (Germany) and Cornell (USA) research projects, which identified the gene responsible for the Glen variant of PRA (progressive retinal atrophy). Initially, with the Bochum project, a number of breed club representatives from the UK and mainland Europe collaborated with the identification of affected Glens, and together they analysed pedigrees to identify close relatives who could also potentially carry the gene mutation. After this came the search for completely unrelated, unaffected Glens (controls). Then began the quest to locate owners and request DNA samples for the research team.
- This highlights the importance of breed clubs, breeders and owners from different countries and continents collaborating with health research projects in this numerically small breed. It also illustrates the time-consuming processes required to identify dogs and collect DNA samples before the scientists can begin their research.

# WHY HAVE A DNA ARCHIVE?



Tamar & Storm at the AHT

The advantage to the research scientists of having a DNA archive is that the identification of affected dogs and the analysis of pedigrees becomes a much simpler and quicker process, because everything required to initiate and progress a health research project is readily available in one place:

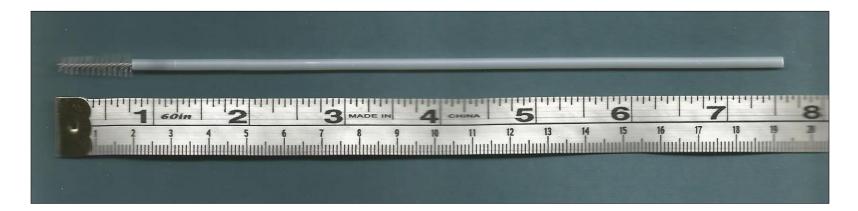
- DNA samples
- Pedigree data
- Health information

### SAMPLE COLLECTION : BUCCAL (CHEEK) SWABS

Please go to this link for video demonstrating how to take swabs from your Glen:

www.efghealth.co.uk/dna\_archive.html#video

• 5 x individually packaged buccal (cheek) swabs : long-handled with nylon-on-wire brush



#### Envelope for the swabs

- Kennel Club registered name and number of dog
- Breed
- Date of birth
- Sex

A H T S C S S S S S S S S S S S S S S S S S S		For Office Use Only
	PLEASE PLACE SWABS FROM A SINGLE D KC Registered <u>Name</u> and <u>Number</u> of Dog	
	Breed	
	D.O.B	Sex
	Envelope for sample swabs only	

- Sample submission form + swabbing instructions (on reverse)
  - Dog details
    - Breed Sex Date of birth DD MMYYYY
    - KC registered name
    - KC registered number
    - Coat colour
    - Microchip or tattoo number (if known)
  - Health information
  - Owner details
    - Name Address Email or telephone contact
  - Declaration

Declaration

I hereby declare that the sample submitted for testing is from the dog described above. I accept that the DNA sample becomes the property of the Animal Health Trust and may be used in future research. I am aware that the dog's name as given may be provided to the breed health coordinator to benefit the sample collection, although all owner details and clinical information or genetic results pertaining to the dog will remain confidential.

Signature \_\_\_\_\_

Date \_\_\_\_\_

#### Sample submission form

	Sample Submission Form
<u>A</u>	1 For office use only
N	Animal Health Trust
Animal He	anus irusi
	SAMPLE SUBMISSION FOR CANINE GENETIC RESEARCH PLEASE WRITE CLEARLY, USING BLOCK LETTERS AND COMPLETE WHERE POSSIBLE
Dog details	
	Sex Date of Birth (D) (M) (Y)
	ered or pet name
	ration number
	and/or tattoo number (if known)
	tatus for possible inherited condition: please lick appropriate box or boxes, indicating diagnoses where relevant.
Affect	ed - please state condition, approximate age, and include copies of veterinary diagnosis
Suspe	acted – i.e. undetermined heritability/lequivocal diagnosis.
G Free	of known inherited disease to your knowledge.
Relat	ed - state condition and relationship to this dog .i.e. sibling affected by
	Swabs or blood sample (please preserve 2-5ml blood in an EDTA tube)
	3 to 5-generation pedigree of the dog whose sample is enclosed.
	All relevant information regarding inherited disease. i.e. copies of eye exams, hip scores, dates of diagnosis
- k	av notes from the clinical history. Essential to make best use of sample
	ay notes from the clinical history. Essential to make best use of sample.
The abov	sy notes from the clinical history. Essential to make best use of sample. Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted.
The abov	e Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted.
The abov to inform	e Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted.
The abov to inform Owner del Name	information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, also
The abov to inform Owner del Name	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, also
The abov to inform Owner del Name Address .	information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, alls:
The abov to Inform Owner del Name Address . Email or b	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, align
The abov to inform Owner del Name Address . Email or b <i>I hereby dec</i>	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, alls: 
The abov to inform Owner del Name Address . Email or b <i>I heraty dec</i> Animal Heat	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, also
The abov to inform Owner del Name Address . Email or b <i>I heraty dec</i> Animal Heat	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, alls: 
The abov to inform Owner del Name Address . Email or b I heraby dec Animal Heat to benefit the	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, also
The abov to Inform Owner del Name Address . Email or b I hereby des Animal Heat to benefit th Signature	Information is necessary for the sample to be used for research purposes. It is also important the ANT of any significant health changes that occur after the sample has been submitted, also: Methods of the sample has been submitted. Methods of the sample has been submitted by the sample has been submitted. Methods of the sample has been be day denother alone. I sample has been have been and be provide of the The fair for sample hashes have been be day denother alone. I sample have been have been also conducter the fair for sample control is future sample. The day denother alone, i sample have been also been also been also The fair for sample control is future sample. The day denother alone, i sample have been also and the sample collection, although all owner details and the day's near a given may be provided to be been also conducter. Date.
The abov to inform Owner del Name Address . Email or b I hereby des Animal Heat to benefit th Signature DNA sample	Information is necessary for the sample to be used for research purposes. It is also important the AHT of any significant health changes that occur after the sample has been submitted, alls: Information of the sample of the sample has been submitted. Information of the sample has been been been been been been been bee
The abov to Inform Owner del Name Address . Email or b I hereby des Animal Heat to benefit th Signature DNA sample	Information is necessary for the sample to be used for research purposes. It is also important the ANT of any significant health changes that occur after the sample has been submitted, also: Methods of the sample has been submitted. Methods of the sample has been submitted by the sample has been submitted. Methods of the sample has been be day denother alone. I sample has been have been and be provide of the The fair for sample hashes have been be day denother alone. I sample have been have been also conducter the fair for sample control is future sample. The day denother alone, i sample have been also been also been also The fair for sample control is future sample. The day denother alone, i sample have been also and the sample collection, although all owner details and the day's near a given may be provided to be been also conducter. Date.

#### Swabbing instructions

	Swabbing Instruction
	Swab Sample Collection Procedure
	Please follow the instructions below carefully to collect the dog's DNA sample. Five (buccal) cheek swabs are provided in each kit and
	are intended for use with one individual dog only. The samples
	should not be taken within one hour after the dog eating to help obtain a clean sample.
	obtain a crean sample.
1.	First label the Swab Envelope clearly with the appropriate KC registered name and number. If these are no
	available, label with the name given on the Sample Submission form. Please also state the breed, sex, an
	birth date of the animal.
2.	Remove a single swab from its packaging, trying to avoid any or excessive contact with the brush enc
	ideally but not necessarily, by wearing latex or vinyl gloves to reduce the possibilities of contamination.
3.	Hold the dog's head firmly and roll the swab on the inside of the dog's cheek on each side of the mouth
	ensuring the brush is moved across the entire cheek surface. N.b. Cheek cells are not visible to the nake
	eye, but please brush the surface thoroughly to ensure a sufficient sample is obtained.
4.	Briefly air-dry the swab for a moment and place directly into the Swab Envelope previously labeled at step 1
5.	Repeat steps 2-4 with the remaining four swabs when convenient and seal the Swab Envelope. All fiv
	swabs can be used during the same sampling session, although this isn't necessary as the dog may becom
	impatient. Use of each swab can be at different time intervals.
6.	Complete the Sample Submission form. It is imperative that the information given here is accurate.
7.	Return the sealed Swab Envelope along with the completed Sample Submission form, and copies of th
	dog's pedigree and relevant health certificates using the return addressed envelope provided, which require
	a large envelope stamp.
	Acknowledgement of sample receipt will be given where an e-mail contact has been provided.
	PLEASE ENSURE WHEN RETURNING SAMPLES THAT THE POSTAGE HAS BEEN PAID
	IN FULL. IT IS NOT NECESSARY TO USE A SPECIAL DELIVERY SERVICE AS THE DNA IS IN A STABLE STATE ONCE DRIED AND PLACED INSIDE THE SWAB ENVELOPE.

PLEASE SEE REVERSE FOR SAMPLE SUBISSION FORM

### SUBMISSION TO AHT

- Addressed envelope provided to:
  - Canine Genetics Centre for Preventative Medicine,
  - Animal Health Trust, Lanwades Park, Kentford, Newmarket, Suffolk, CB8 7UU, UK
- Checklist:
  - **5** swabs (or blood sample : 2 5mls in EDTA tube : please refer to slide 3 regarding blood samples)
  - $\Box$  3 5 generation pedigree
  - All relevant health information
    - If applicable, <u>copies</u> of health screening certificates e.g.
      - □ (latest) eye examination ~ hip/elbow scores ~ DNA test result for crd3
    - If applicable, information & (if possible) <u>copies</u> of supporting documentation for diagnosed health conditions
      - □ dates of diagnoses ~ key notes from medical history ~ blood test results ~ X-ray / scan reports ~ histology reports, etc.
  - N.B. Please do not send the originals of health screening certificates and supporting health documentation

### SUBMISSION TO AHT



- Blood samples sent from non-EU countries require an import licence reference – please write <u>PATH/III/2009/I</u> in bottom right-hand corner of envelope
- Swabs & blood samples posted from outside the UK can be sent via:
  - > airmail
  - > or, if preferred, surface mail

### COST TO OWNERS

- The AHT requests a small donation of £5.00 (GBP) per swab kit to cover:
  - cost of swab kit
  - Iong-term storage
  - administrative costs
    - 5 GBP = 6.3 EUR
    - 5 GBP = 8.4 USD
      - (02 August 2014)
- A facility has been set up for non-UK owners to make their donations via PayPal ... using their own PayPal account or a debit or credit card
- **N.B.** There is a small charge for making donations via PayPal : <u>http://www.efghealth.co.uk/dna\_archive.html#donation</u>

# HEALTH UPDATES & NOTIFICATION OF DEATH

- It is important to keep the AHT and the confidential Glen Health Database updated of any changes to a Glen's health status:
  - Diagnosis of any new health condition, including date of (or age at) diagnosis
  - Date & cause of death
  - Email the Animal Health Trust : <u>canine.genetics@aht.org.uk</u>
  - Email the confidential Glen Health Database : <a href="mailto:efghealth@gmail.com">efghealth@gmail.com</a>

### CONFIDENTIAL GLEN HEALTH DATABASE

- The pedigree data and health information provided by owners remains confidential to the Animal Health Trust.
- So, to help us with our breed health monitoring, we ask owners ... if they are happy to do so ... to provide health information about their Glens, using the printable form (next slide) or via our online form:

www.efghealth.co.uk/dna\_archive.html#db

### CONFIDENTIAL GLEN HEALTH DATABASE

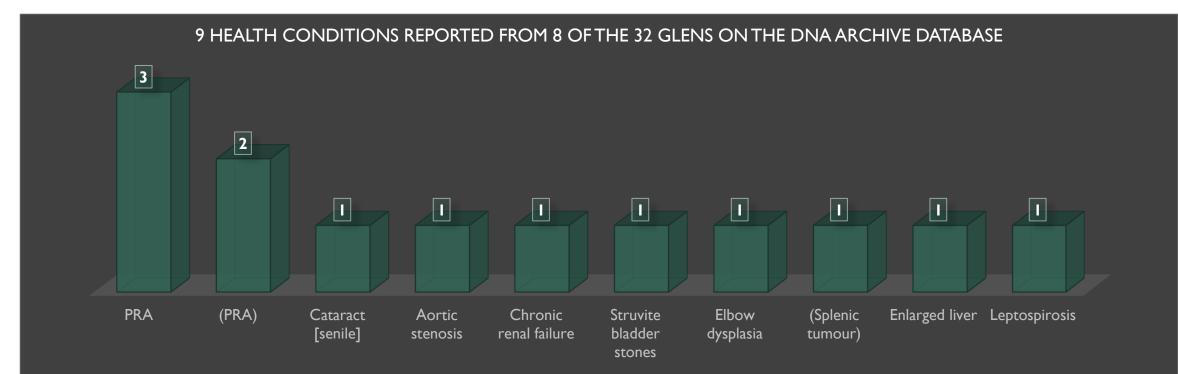
Information before requested for our confidencial health databased BigInomation before requested for our confidencial health databased Texture in the set of the confidencial health databased Determine the set of the confidencial health databased Texture in the set of the set		EN OF IMAAL TERRIER DNA ARCHIVE AT THE ANIMAL HEALTH TRUST (AHT) Request for AHT DNA swab kit
GEN DITAILS           Registered name:           Pet name:           Date of birth:         e.g. 01 Jon 2000           Ser:              Obge mitre: Diag modered:              Birth name:           Date of birth:         e.g. 01 Jon 2000              Birth name:              Birth name:           Birth:         e.g. 01 Jon 2000              Birth name:              Birth name:         <		
Registered name:		(information below requested for our confidential health database)
Pet name:	GLEN DETAILS	
Data of birth:       e.g. 01 Jen 2000         Ser:       Image notify the line in the Line Line Line Line Line Line Line Lin	Registered name:	
See:              Oog endire               Bach spaysed            Has your difees work been diagnoods with any serioux, ongoing or recurrent health condition/17             IN o               No o            Hard-please specify the condition/12               No o               No            Partiel-please specify the condition/12               No               No               No            Further information:                  No	Pet name:	
Has your Gleen ever been diagnosed with any serious, ongoing or recurrent health condition(s?)       IN ID Yes         If "ed" - please specify the condition(s:	Date of birth:	e.g. 01 Jan 2000
If "ter' - places specify the condition/s:	Sex:	Dog entire Dog neutered Bitch entire Bitch spayed
Date and/or age of diagnosis:           Further information:           Further information:           OWNER DETAILS           OWNER DETAILS           Tide/s:           Sumane/s:           Address:	Has your Glen ever beer	n diagnosed with any serious, ongoing or recurrent health condition/s?
Further Information:           OWNER OFTAILS           Tride/s:           Surname/s:           Addres:	If 'Yes' – please specify	the condition/s:
OWNER DETAILS           Tridy/s:           UMr © Mrs © Ms © 0r © Other	Date and/or age of diag	nosis:
Title/s:         D Mr Mis Mis Dir Other           Sumame/s:	Further Information:	
Title/s:         D Mr Mis Mis Dir Other           Sumame/s:		
Title/s:         D Mr Mis Mis Dir Other           Sumame/s:		
Title/s:         D Mr Mis Mis Dir Other           Sumame/s:	OWNER DETAILS	
Sumame/s:	Title/s-	DMr DMr DMr D0r D0ther
Print name/s: Address:  Email:  Telephone number/s:  Office are only:  Amount: L		
Address: Email: Telephone number/s: Office are only: Anount: [ Dichegve D Cesh		
Email: Postcode: Telephone number/s: Offer are only: D'Cheque D'cash		
Email: Telephone number/s: Office site only: Amount: <u>E</u>		
Email: Telephone number/s: Office site only: Amount: <u>E</u>		
Email: Telephone number/s: Office site only: Amount: <u>E</u>		Postrode
Telephane number/s:	Fmail:	
Office use only: Amount: <u>E</u>		
Donoton mc'd (dans): Sweda supplied (dans):	Office use only:	Amount: <u>E</u> ChequeCosh
		Donation rec'd (date): Swebs supplied (date):

www.efghealth.co.uk/kitrequest.pdf

Information requested:

- Dog details
  - KC registered name & pet name
  - Date of birth DD MMYYYY
  - Sex : neutered or entire
- Health information
- Owner details
  - Name Address Email / telephone contact

### HEALTH INFORMATION



### LINKS & CONTACTS

### Animal Health Trust

www.aht.org.uk/cms-display/what\_we\_do.html



EFG Health DNA Archive page

www.efghealth.co.uk/dna\_archive.html



Canine Genetics Centre for Preventative Medicine Animal Health Trust Lanwades Park Kentford Newmarket Suffolk CB8 7UU UK Alison Seall, DNA Archive Coordinator Email : <u>efghealth@gmail.com</u>

# INTERNATIONAL ARCHIVE ...?

- The Glen is a numerically small breed ...
- The Glen PRA research projects (Bochum & Cornell) demonstrated the importance of cooperation and collaboration between countries to facilitate the collection of enough DNA samples for the scientists
- The AHT accepts samples from dogs resident outside the UK
- The AHT is happy to provide aliquots of DNA to research teams
  - These samples are anonymised
  - It is indicated whether DNA samples are from affected or controls for a particular condition
- An international DNA archive brings DNA samples, pedigree data and health information together in one place and provides "one-stop" access for future health research projects …
  - \* The first four DNA samples for the Glen of Imaal Terrier DNA Archive were received by the AHT on 1st November 2013



### PLEASE SUPPORT DNA ARCHIVING ...

... for the future benefit of our lovely breed THANK YOU!