

# STCA-HTF Scottish Terrier DNA Bank FAQ's

## What is a DNA Bank?

DNA Banking involves the long-term, secure storage of DNA samples and genetic data generated from specific animal samples. Today, there are human ancestry DNA Banks such as 23AndMe as well as livestock DNA Banks already in existence and a DNA Repository for dogs with OFA's Canine Health Information Center (CHIC).

## Why should I send my Scottie's sample to the STCA DNA Bank?

The purpose of the STCA DNA Bank is to preserve DNA from as many Scottish Terrier bloodlines as possible. By establishing the STCA DNA Bank, we will have a permanent repository of our breed's genetic heritage for future health research studies that could benefit all Scotties. There are dogs alive today from most of the foundational bloodlines of the Scottish Terrier breed, both here in the US and from around the world. These dogs and their descendants carry the genetic heritage of our breed. With technology advancing rapidly and becoming more affordable, we want to position the breed to take advantage of new tools as they become available, helping us understand the genetic basis of both healthy traits and abnormalities. Now is the time to get ready for our future.

## Where will the STCA-HTF DNA Bank be located?

The STCA HTF has an agreement with Resero Genomics in Salt Lake City, Utah to receive blood and other samples of our Scottish Terriers. Resero will extract DNA and build the Scottish Terrier DNA Bank for us.

## Why not just use the CHIC DNA Repository with the OFA?

The key difference between the STCA-HTF Scottish Terrier DNA Bank and the CHIC DNA Repository is ownership of the DNA Samples. When samples are sent to the CHIC DNA Bank, the owner must sign a release form, relinquishing all control, knowledge, and decision making as to how the DNA is used. By contrast, with the STCA-HTF Bank, ownership and permission to access the dog's DNA will remain with the designated owner. With the STCA's DNA Bank, owners can have their dog's DNA sent elsewhere for analysis, donate their Scottie DNA for research purposes of their own choosing and even withdraw their dog's DNA from the bank at any time. In other words, Resero Genomics will process and store the DNA, but the owners do not relinquish control of their dog's DNA to another entity, unless they choose to do so.

As the assigned Manager for the DNA Bank, the HTF's DNA Committee will keep owners informed regarding any health research studies that might benefit from access to the DNA Bank. The Committee anticipates that most owners will agree with these recommendations without reservations, but the owners will have the choice.

Over the years, Scottie owners and breeders have generously contributed samples to many studies. But far too many times, irreplaceable genetic material has been lost and is now unavailable to us. The DNA from entire families of Scotties has been used in major research projects such as Cerebellar Abiotrophy (CA) and Scottie Cramp, with no applicable results. Now many of these precious dogs are gone, and their DNA is not available for future use. We can't let this happen any longer. With the STCA DNA Bank, we will have an affordable method to preserve Scottish Terrier DNA for the future.

## Will my Scottie's DNA sample be stored in a safe and secure manner?

*Resero Response: The security of your DNA is important to Resero Genomics because we know it is important to you. We have successfully stored and maintained both animal and human DNA since 2003.*

*We set criteria for our biobank with the intent of storing a DNA sample for over 50 years that meets the quality needs for genotyping and sequencing purposes. We have developed fail-safe methods to protect against even the most unlikely catastrophic events. Two separate DNA samples using two different methods and two different locations will build a fail-safe system for the Scottish Terrier DNA Bank.*

## **How are the DNA samples stored?**

Resero Response: *We are able to offer storage in ultra-low temperature freezers, cryogenic liquid nitrogen tanks, and dehydration (dry) storage. We strive to store each DNA sample using two different methods in two different locations providing back-up security of Customer DNA.*

## **How long can DNA samples be stored?**

Resero Response: *No one really knows! Maybe forever if properly handled. We use the best methods in the industry to preserve each sample for long term use. Integrity of the DNA is very important for correct analysis to derive the best information for you, the Customer. We guarantee high quality DNA for at least 50 years. Again, no one really knows. DNA is being discovered in frozen tundra that is many centuries old and still have enough integrity for valuable sequencing projects.*

## **What happens to my DNA samples if Resero Genomics goes out of business?**

Resero Response: *In the unlikely event that the Resero Genomics business is dissolved or sold, every conceivable precaution is taken to protect your banked DNA that has been entrusted to us. In this circumstance, we will notify you well in advance of any change in ownership or dissolution to give you the option to re-direct your DNA to another location of your choice. This unlikely occurrence is explained in detail in our Standard Agreement.*

## **Who owns the DNA and Data?**

Resero Response: *You own all the DNA that is submitted to, or extracted by, Resero Genomics using your submitted samples. You own and control all information derived from the DNA by Resero. When you submit samples for processing, we will ask for ownership information. You will designate who the owner is and who is authorized to have access to the DNA. Ownership of the DNA will always fall to the entity designated in records kept on-file for each sample. Changes to that ownership will be properly updated as received from the ownership of the originating sample.*

HTF Comment: The STCA HTF is listed as the Account Manager for each DNA Sample submitted to Resero Genomics. However, the User Provisions Agreement for participating in the STCA DNA Bank states that the dog's owner will retain control of their Scottish Terrier' DNA.

## **Who has access to my samples?**

Resero Response: *You, the owner, decide who has access to your samples. At the time of submission, you will grant Resero Genomics authorization to extract DNA, store, and maintain your samples under the named owner(s) of the DNA, and you will indicate who has future access. Resero Genomics will not access or use the DNA for any reason without consent from the owner(s) named. We will also not allow anyone else to access the samples without written consent of the owner. If access to the DNA is granted to the STCA-HTF, then the manager of the Scottish Terrier DNA Bank will be the contact person for updating Ownership and Access changes as needed. More details on this are being drafted by the STCA-HTF.*

HTF Comment: The STCA HTF has established a DNA Committee that will oversee the STCA DNA Bank and will establish recommendations for HTF approval on how the DNA Bank samples will be used.

## Who decides how the samples are used?

The HTF's DNA Committee will keep owners informed about all plans and proposed research projects. You (the dog's owner) retain ownership of your dog's samples and retain ultimate control of how these samples are used.

## Can I transfer ownership of my samples?

Yes. The owner can change ownership by providing written instructions to the HTF's DNA Committee. You will need to fill out, sign, and return a change of ownership form to the Account Manager designated by the STCA-HTF to oversee the Scottish Terrier DNA Bank. The DNA Committee will then provide instructions to Resero Genomics as appropriate.

## How much does it cost to store canine samples?

There are two options available at Resero Genomics to Scottie owners:

**Option #1 The STCA-HTF Managed Account:** This account has been established with Resero Genomics, and will be maintained at no cost to you. You will be responsible for the collection of the blood sample by your veterinarian and mailing of the sample to Resero Genomics. Specialized blood collection tubes will be provided by STCA-HTF to allow room temperature storage and inexpensive mailing of the sample to Resero Genomics for DNA extraction. When you submit a sample, you (the owners) will sign a Resero Sample Submission Form and agree to include your dogs' DNA in the STCA-HTF Managed DNA Account with Resero Genomics. All costs for extracting the DNA and the yearly storage fees will be covered by the STCA-HTF. You will agree to allow the HTF to manage the account and to have access to the stored DNA for research purposes, but only with your consent after full disclosure of how the DNA will be used and how the information derived will be communicated.

In return for having all DNA banking fees paid by the HTF, you will complete an on-line application for the STCA-HTF Database and will also provide additional information about the dog, including contact information for any co-owners, the dog's registered name, AKC number, pedigree information, health history, etc. If the dog being entered into the database is not registered and thus has no AKC number, then a unique number will be assigned to it. All information on the dogs entered by the owner including names, registration, pedigree and other identification and health data will be viewable and searchable by the public. Personal contact information of the owner(s) entered in the Database will be kept in strict confidence and be available **ONLY** to the STCA-HTF DNA Database Admin and HTF Manager.

**Option #2 Individual Account:** This account will need to be established by you with Resero Genomics, and you will bear all costs for sample collection, DNA extraction and annual storage, and you will be billed directly by Resero Genomics for all samples submitted. The total annual storage cost for an individual account will depend on the number of samples in the customer's inventory. (All pricing information can be found on the Resero Genomics Banking Order Form.)

## Will my samples be used in research studies?

Access to DNA by the STCA HTF DNA Committee for future health research is an integral part of the STCA-HTF Managed Account option. The HTF DNA Committee will research opportunities to have your samples involved in proposed research studies, and genetic researchers who are aware of the DNA Bank may request access to DNA samples or genetic data for their research projects. However, access will not be granted without the consent of the owners and full disclosure to the STCA membership about the study and how it could benefit the Scottish Terrier breed.

## **Will I receive data or test results if my samples are used in a study?**

This will depend on the study and the arrangements made with the researcher. The researcher requesting access to your samples will first submit a proposal. The STCA-HTF DNA Committee will review the project plan and verify the researcher's credentials to ensure that this study will be beneficial to the Scottish Terrier breed. This information will then be communicated to you, and you will have the option to opt out of participating in the study.

## **How secure is the Database managed by the HTF?**

Contact information for owners and supporting veterinary records will be maintained in a secure database monitored and verified by the appointed HTF Admin and a select STCA HTF DNA Committee. Dog owners will have access to create an account, enter and update their own dogs' data using a secured log-in process.

## **What information in the Database will be available to the general public?**

Each dog's identity and associated health information will be viewable and/or searchable by the general public. This means that registered names, sire and dam, identifying information, and all health history listed by the owner will be available to the public. Health information listed by the owner will be considered anecdotal until supporting diagnostic documents have been received. Any supporting veterinary records submitted by the owner to document the record will be archived for research verification purposes and **will not** be available to public view. Names and contact information of the owner(s) **will not** be viewable or searchable by the public and will be kept strictly confidential. There will be a designated overseer (STCA-HTF Scottish Terrier DNA Bank manager) of the entire database to review aggregate data and track significant trends in the population of Scotties with respect to reported health issues and genetic disease incidence. Owner names and contact information will be used in private communications by the DNA Committee to keep owners informed.

## **Can I order genetic testing from Resero using my banked DNA samples?**

Resero Response: *Yes. DNA from your banked samples can be used for genetic testing in the future, eliminating the need to recollect and extract the sample for testing. Resero is constantly updating the list of available tests for all species. By having stored DNA on your dogs, you will NOT need to collect a sample from your dog again. It is done and sample DNA will be available for several hundred DNA tests and for future sequencing efforts if needed.*

## **Does Resero currently offer genetic tests accepted by OFA for the Scottish Terrier CHIC Registry?**

HTF Comment: Yes. The OFA has approved Resero as an accepted lab to offer the DNA tests currently required by the STCA for Scotties in the CHIC Registry. At this time, Resero will offer the von Willebrand Disease (vWD) and Craniomandibular Osteopathy (CMO) tests and any other DNA test that may become a requirement or an option for CHIC certification in the future. The CHIC registry will remain a searchable registry option for Scottie breeders and owners to record their test results and earn a CHIC number for each of their dogs.

## **Can I send my samples to another genetic testing company for testing?**

Resero Response: *Yes. You can transfer a sample of the DNA stored on your dog to any entity you choose, provided that there is enough DNA in storage to meet the amount required by the third-party lab. Once the samples have left the DNA Repository, we can't guarantee quality or safety of the sample*

*or how it will perform in the receiving laboratory using their analyses systems. Cost to send a sample for testing at another facility is \$5.00 per DNA sample.*

HTF Comment: The Provisions Agreement for participating in the STCA DNA Bank includes an option for requesting that a portion of the DNA sample be used at another company. An owner should submit their request to the HTF DNA Committee for approval.

**I've already sent a sample to another DNA Bank or genetic testing company.  
Can that sample be relocated and stored at Resero?**

Resero Response: *Yes. We can accept samples from other DNA banks or genetic testing companies that have your sample. Once the DNA reaches our lab, we will assess the quality and total amount of DNA received and report back to the customer. We will only store DNA if it meets our quality standards and we will advise you if there are issues with the quality and amount received. It is important to note that if the third-party lab has obtained ownership of your DNA, they will be considered the owner unless that ownership is transferred to you. Please contact us for proper forms to complete this transfer process.*

HTF Comment: Please review the answer to a previous question regarding two (2) options for establishing an account at Resero Genomics. Individual accounts are owned and paid for by the individual owner. The STCA DNA Bank is managed and paid for by the STCA in accordance with a separate Provisions Agreement. Please contact the DNA Committee if you would like to transfer a DNA sample stored in another Bank to the STCA DNA Bank.

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