

Health Registries: What can we learn from human registries and why should we want one for Bearded Collies?

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Some countries routinely record health information from their people. This registry information, much of it from northern Europe, has provided researchers with key data for understanding important diseases and whether there are links to genetics or to lifestyle factors or both. For instance, some of the critical early work associating cigarette smoking with lung cancer and lung diseases such as emphysema used registry data from Sweden. In contrast, disease-specific registries record information on rare or poorly understood conditions; over time, enough information is accumulated to allow researchers to analyze it and draw conclusions. Fifteen years ago, I was one of the first women to enroll in a registry for women who used an antiepileptic drug during pregnancy. Years later, that body of information allows women and doctors to make informed choices about which drugs to use while a woman is still planning a pregnancy.

Both of these examples are directly applicable to Bearded Collies and the people who love them. One of the reasons Sweden's human health information registry was and is so useful to medical researchers is that it represents generations of people with a relatively common ethnic background. In the same way, Beardies have a common gene pool: they represent one breed. We know information from a single-breed registry is relevant to that breed, while general canine information may or may not be. Indeed, Beardies throughout the world have a very tight gene pool.

One positive is the knowledge that all genetic information applies to all Beardies, wherever they live. If a condition known to have some genetic links differs significantly among different geographical locations, researchers can consider what environmental factors may affect occurrence of the condition. Although it is a negative that we have such a tight gene pool in Bearded Collies, a large representative registry can provide information that allows breeders to make the most informed breeding decisions possible regarding health conditions.

We know hip dysplasia is due to the influence of multiple genes. Accumulation of information on Addison's disease that began with a broad-based survey by the American breed club allowed researchers to realize that susceptibility to Addison's disease reflects the interplay of several genes. Ongoing research is trying to identify what genes and develop a test for at least the most influential gene.

We have an international open health registry for Bearded Collies run by BeaCon, the nonprofit Bearded Collie Foundation for Health.

What we need is information on as many dogs as possible from as many parts of the world in order to develop a multi-generation pool of information that can accomplish two key goals:

1. Provide breeders with information that allows them to make the most informed health-based choices for any prospective mating
2. Provide researchers with information that can allow them to advance health testing and health care for all Beardies.

All members of the Beardie community must ask at least some of the following questions occasionally:

1. Do I know the average life expectancy of my Beardie puppy?
2. Is it longer than that of the generations before it, the same, or shorter?
3. Do I know the most common causes of death and when death occurs?
4. Do I know the five most common health problems?
5. Do I know whether there is research to show genetic influences play a role or not?
6. Are the diseases of yesterday the same as today?
7. Are we improving the health of our breed?

The only requirement for participation in BeaCon is that the dog be a purebred Bearded Collie with known parentage. The owner and dog can reside in any country and the owner does not have to be a member of any Bearded Collie club. Indeed, every owner and every purebred Beardie with known parents (knowing the parents enables breeders and researchers to use the information to construct pedigrees and then make breeding decisions or conduct a genetic analysis) should be in the registry.

Every registry is only as good as the quality and quantity of its information, and the most comprehensive registries have shown their value in medical research time and time again.

One reviewer of the CD of Beacon's Open Registry commented: "Excellent work? I wish all breeds could follow your example . . ." In answer to the question "What Needs Improvement?", the reviewer wrote "more dogs."

Another reviewer of a the 2001 registry report wrote "Your open registry represents several years of good work. The many volunteers who contributed to this open registry must be recognized for the service they provided to their breed. Individual records, reproductive history, male reproduction, health problems & owner information are key ingredients to your database. The next step for your board would be to develop a strategic plan for your open database. It must include cumulative data and reports that begin to tell the story. Then there must be articles about how to use the system, how to interpret the data, and what each breeder needs to be doing. This is a great start, now the Board needs to develop a short and long range plan".

In the spring of 2010, the Year 9 registry report was published. BeaCon thanks the people who registered dogs and did the yearly updates that have allowed the accumulation of longitudinal data, data that begin to tell a story over time rather than information for one point in time. There is a tutorial on the BeaCon website to walk prospective users through the registration process. The registration questionnaire is also available in a few languages other than English.

If it seems too intimidating to consider registering all of your dogs, do one at a time, perhaps a bitch before she is bred or a new puppy. The process is really quite short when a dog is healthy. Good health screening tests (hip scores, thyroid values, eye exam results) can be documented by sending the certificate or lab result form. (Note: 2013 – now these data are readily accessible at the OFA registry – www.offa.org – for USA dogs).

Medical conditions can be documented by sending a lab form or veterinarian's letter. On rare occasions another person has challenged a diagnosis entered. Owners can self-report diseases.... The quality of the documentation is recorded for each dog so each user of the registry information can decide how to weigh it in their own thinking. Obviously, medical

documentation helps the most. Sometimes, however, especially for a dog who has died or been ill for a long time, it is not possible to get the original diagnostic information. Each person should simply do the best they can in providing information. Many people call their dog's breeder when their dog gets sick. If you no longer have the health paperwork but sent copies to your breeder when your dog first got sick so they could better understand what was happening, consider asking them to help document the dog's illness.

Truthful, quality information can help everyone. Ignorance never helps anyone. Ask questions about the registry and other efforts of BeaCon. Support it in any way you can. BeaCon is a registered charity corporation in the USA. Its information is available to everyone. Do it for the dogs. They love us as much as we love them.