

## Breaking the Silence An Odyssey in Renal Dysplasia - Part 1

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The Dog Writers Association of America awarded this three part series a Certificate of Excellence in the category of Magazine Subject-Related Series in 1997. The series was originally published in The Lhasa Apso Reporter.

Dear Readers,

I am very pleased to tell you that beginning with this issue, Debby Rothman of Fleetfire Lhasas has graciously agreed to share with all of us her experiences in dealing with renal dysplasia, a deadly disease found in our beloved breed. Debby has done extensive research about RD, through veterinary journals and personal conversations with experts, but also in dealings with her own Lhasas.

Having lost a six-month-old puppy to RD in 1992, I know the sadness one can feel in losing a dog to a genetic illness. While the loss our puppy was quite sad and unfortunate, he was not related to our other dogs and therefore the death did not have far-reaching consequences for our own breeding program. I can only begin to imagine the pain and sadness Debby and any other breeder must feel when a disease such as this is found among their breeding dogs.

In the next year we will hear some bad news, but we will also hear some good news. We will hear about a company that is trying to find a genetic marker for this tragic disease, a possible non-invasive test that may come about to diagnose RD, and about some of the research going on to treat it. I call upon all of you to read these articles carefully and discover what you -- as the caretakers of our breed -- can do to help fight this disease. It is time we all band together to help the experts find a test to determine carriers of RD, help them find a genetic marker -- and most of all - learn how to structure our own breeding programs to avoid breeding carriers and puppies with RD.

And there are things you can do to help. Stay with us, and we will keep you updated.

Jenny Drastura

## Breaking the Silence An Odyssey in Renal Dysplasia

In June of 1996, after nearly 60 champions and years of successfully breeding to the standard, my breeding program came to a crashing halt. I received the devastating news that a puppy I co-bred and co-owned had Renal Dysplasia. This beautiful puppy represented five generations on both sides of the pedigree, 16 years of work within my breeding program. She also represented 12 years and several generations of Julie Timbers work. Her sire, an exquisite dog, won both of his majors at specialties. Her breathtaking dam is a specialty winner from the classes. While the deep valleys are farther apart as time goes on, it has been a roller coaster ride, playing havoc with our minds, emotions and breeding programs.

Renal Dysplasia is a disease that affects the development of the kidneys. All dogs are born with immature kidneys, made of fetal kidney tissue. By about eight weeks of age, the kidneys will have developed into mature kidneys. This transition does not complete itself if the dog is affected with Renal Dysplasia. It is manifested by the presence of fetal or immature glomeruli and/or tubules within an otherwise mature kidney. (1.) The percentage of immature glomeruli is what determines how affected the dog is. The dogs

are classified as normal, borderline, mildly affected, moderately affected, moderately severe and severe. The degree of affectedness determines the dog's life span. Mildly affected dogs will live an asymptomatic lifespan!! (2.)

To make matters even worse, the breeding had basically been repeated - same sire bred to a sister of the dam of the RD puppy. What about my expected litter? I didn't know where to turn. There were so many questions. What I would have given to have been able to contact another Ihasa breeder that had successfully dealt with RD in a breeding program!

I remembered an article written by veterinarians at the UN of MN (3.), as well as an article about RD in the AKC Gazette, in a shih tzu column (4.). My friend searched the net, looking for information on breeds with RD. My vet did a search through his veterinary resources for information. Although it was bits and pieces, it was a place to start. Each lead led to at least one more, and so I gathered information. I read and studied the information. I talked with knowledgeable veterinarians, researchers and geneticists. I wrote to every university that has a grant for any kind of kidney research in any breed. I realized that most research in the past focused on the treatment of animals with RD or the underlying pathology of the disease. There was little available on how to deal with RD within a breeding program.

There were days when it all seemed so overwhelming; I felt like I couldn't go on. What was I to do about my breeding program, my passion, my work? What about the expected litter? How should I deal with that? What about my beautiful dogs, a product of my creativity and my passion? I felt like I was responsible for giving them this dreaded disease. I felt like I caused it. That was the hardest feeling to get over. It took months before I stopped blaming myself and was able to talk about it without breaking down.

Besides my close friends, there are three breeders that have helped me deal with the emotions and the decisions I faced.

Patricia Craige Trotter, Vin-Melca Norwegian Elkhounds, was the first breeder I contacted because one of the articles mentioned that Elkhounds also have this disease. She has had my respect for years because she consistently breeds outstanding dogs. Mrs. Trotter lived up to my expectations and responded immediately. I would like to quote parts of her letter because it has been a source of inspiration for me.

"First of all, you have taken the most important step of all,,, identifying the problem and recognizing it... i.e. verbalizing it. That is painful and involves self-awareness as well as responsibility and accountability. You are not the first person who has inadvertently made breedings that come back to cause pain and suffering. You will not be the last. The big thing you have going for you again, is admitting it, facing it head on and trying to cope with it..... Try to research and find out everything you can about the disease and its hereditary behavior. And keep in mind that in time it will sort itself out.... right now is as bad as it gets. In other words, keep the faith."

Mrs. Trotter also invited me to meet with her at a show in Colorado, where she was judging hounds, in August. That meeting was very difficult because I was still unable to talk, face to face, and not break down. Her compassion and concern, as a fellow breeder, has given me solace.

Janet Edwards, chairman of the American Shih Tzu Club's RD committee, was another person I contacted immediately. She sent me a very helpful information packet. Most of the literature was written by Dr. Kenneth Bovee of the University of Pennsylvania. He has been studying this disease, including the mode of inheritance since, at least, the early 70's.

In Janet Edwards' letter she writes "Back in the early '70s when I first got into Shih Tzu - my first litters were all affected with RD..... Of course 'no one had ever had this problem and it was something I had done that

had caused this to happen.' So I stayed with the same bloodline - changing breeding dogs - and the same thing continued to happen.

"In the mid-70's," continued Janet, "I contacted Dr. Bovee and talked my vet into doing kidney biopsies, changed bloodlines and biopsied all dogs kept for breeding. They do not know the mode of inheritance for sure so I approach it like trying to breed out hip dysplasia. Use dogs with normal biopsies for breeding and as those dogs 'accumulate' in the pedigrees the chances increase of you producing normal pups. This has worked for me. Don't give up you'll get yourself out of this!"

Wasn't her approach drastic? Invasive wedge biopsies? Wasn't there some other way to do this? What was I going to do with my litter? Couldn't I screen my litter with BUN, creatinine and specific gravity tests? Couldn't I have their kidneys ultrasounded or x-rayed? Surely I wouldn't need to have surgery performed on my dogs. Would I? There must be another way!

Through a chain of events I met Donna Rogers, a Soft Coated Wheaten Terrier breeder, who has helped more than I ever would have thought possible. She presented my situation to the genetic scientists at VetGen. Donna, having dealt with RD for several years, is further along in the entire process than I am. She is committed to finding answers and educating people. She helps me through the bad times and there still are plenty of those. In one of our first conversations Donna said I had to get to the place in my heart where I no longer blamed myself. Intellectually, I knew I didn't give this to my dogs, but in my heart I felt responsible, so I knew exactly what she meant. We've cried together and we've laughed together about situations that arise that only someone dealing with RD could understand.

In August, still unable to talk what was happening without breaking down, I attended our local club's meeting. Ironically, it was the day after my meeting with Pat Trotter. The subject of kidney disease came up. Misinformation and accusations were flying around the table. Is this why breeders don't want to talk about this disease in public? I didn't utter a word. I couldn't. I sat, mute, with more information on RD than anyone at the meeting. I had to leave the meeting. I drove home on the back roads, pointing my car down *any* road, as long as it was a quiet country road, that headed in the general direction of home. I was mad, sad, and hopeless. *Why oh why was this happening to me? Why?*

As time went on, it got easier to talk about. I've informed the ALAC board of my situation, as well as the members of my local club and some other breeders. I am now able to converse on a rational level, anytime, about RD.

But what about my puppies? Four bitches and one dog were born July 5, 1996. Adding insult to injury, four out of the five were liver pigmented! I haven't had a liver pigmented dog in years. I thought I'd had taken care of that! Here was a not so gentle reminder of genetics and the strange things genes will do. All I could do was laugh! At least they weren't going to die from liver pigment! That was the least of my concerns. My worst suspicions were confirmed when the male puppy was euthanized because of a brain infection (diagnosed after necropsy). His kidneys were sent to the University of Pennsylvania. Dr. Bovee's report came back - moderately affected with Renal Dysplasia.

The liver pigment turned out to be a blessing in disguise. Three puppies would be spayed because of the liver pigment. The puppies couldn't be placed until I knew the status of each puppy's kidneys and that the puppy would live a normal lifespan. How was I going to guarantee that? A wedge biopsy read by a specialist, is the *only* way to know if a dog is affected and to what degree. What if my vet, Dr. David Manobla, spayed them and biopsied them at the same time? This was not an easy decision. It took 4 months to make the decision to have the biopsies performed. It was the right decision. It was a wise decision. It was a decision that will hopefully affect all breeders.

In addition to the three liver pigmented puppies, biopsies have been done on their sire and three older

dogs. The three older dogs had normal kidneys, but the puppies and their sire weren't as fortunate. The sire is mildly affected with 5% fetal glomeruli. Latte is also mildly affected with 4% fetal glomeruli. These two dogs will lead an asymptomatic normal lifespan. Mocha and Chiata are not so lucky. Chiata is severely affected with 40% fetal glomeruli. She has an expected six month life span. Mocha is moderately affected with 15% fetal glomeruli and has a one to two year life span. *It is important to note that, in spite of this diagnosis - Chiata and Mocha's BUN, creatinine and specific gravity tests are normal right now! These test values are not enough to diagnose RD!*

The biopsies performed on the puppies, their sire and the older dogs supplied VetGen with tissue from normal kidneys and affected kidneys for their studies. VetGen is the canine molecular genetics company that developed the marker test for Copper Toxocosis in the Bedlington Terrier; and the von Willebrand's marker test in both the Scottish Terrier and the Doberman Pinscher. The company is developing a test for Renal Dysplasia that will identify not only affected dogs but also carriers. VetGen has confidence that, with the help of this tissue and DNA I've been able to supply, that a non-invasive marker test for RD will be available in the future. The DNA is collected, simply and painlessly, with a small brush that is about 4 inches long. The brush is twirled in the cheek of the dog for 15 seconds. Every DNA sample submitted is coded, making references to a specific dog's identity and genetic status entirely confidential. (5.) If you are willing to provide DNA samples from affected dogs contact either myself or Rob Loechel at VetGen, 1-800-4-VetGen.

If it had not been for Julie's persistency and Dr. Tim O'Brien, a pathologist at the University of Minnesota with special interest in the kidney, we would still be unaware of the problem! *It is extremely important to work with urinary specialists because although the disease is familiar to veterinary urologists and many breeders, it has only been superficially described in the veterinary literature.* (3.)

Dr. Ken Bovee, University of Pennsylvania, who has been studying this disease and its mode of inheritance for more than 20 years, interprets the pathology reports and makes the diagnosis and prognosis for each animal that we've had biopsied. Dr. Bovee also requested all of our dogs' pedigrees to further his studies. All biopsies that we've had done since the original diagnosis are sent to: University of Pennsylvania, School of Veterinary Medicine, Laboratory of Pathology, 3800 Spruce Street, Philadelphia, PA 19104-6051, attention: Dr. Michael Goldschmidt. The phone number is 215/898-8857.

I still have bad days. I've been asked why I would let anyone know this is happening to me. I've been told I'm going way overboard. I've been told I'm brave. I don't think either is true. I just know that I'm doing what I have to do. *I am Breaking The Silence.*

*Debby Rothman can be reached on Mondays, Tuesdays and Wednesdays at 303/674-3297. Please leave a message. If she can hear you, she will pick up the phone, otherwise she will return your phone call. Her e-mail address is: [LhasaLhady@aol.com](mailto:LhasaLhady@aol.com).*

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