

you have an affected dog. As an owner of an epileptic dog you are the one living with the reality of the disease on a daily basis, whereas many breeders who produce affected dogs and carriers are not. You have more expertise from your personal experience than you may know.

**3. Find out how widespread the problem is within your breed.** What percentage of dogs within your breed are epileptic or are carriers? What research is being done? Don't be surprised if you discover some resistance to your questions and inquiries. Since Idiopathic Epilepsy is genetic some breeders may be defensive and may not recognize that it is a problem. They may be reluctant to support research efforts or organizations that seek to raise awareness about canine epilepsy. If it affects their own bloodlines, they may be more likely to deny the serious nature of the disease and may even seek to cover it up.

**4. Join or start a discussion group about epilepsy in your breed.** Seek out other members of your breed club who are joining the fight against epilepsy. You will find that there are breeders that have the courage to talk about the problem. In our breed there was a lot of silence about

epilepsy until a few breeders who had produced it had the courage to begin talking about the disease and formed a discussion group, EpiGENES, in August 2003 at yahoo.com. EpiGENES was created to encourage dialogue about the problem in our breed in an effort to stop epilepsy. Since a lot of our conversations are sensitive, EpiGENES is a confidential discussion group in order to create a safe environment for open and honest dialogue and to share information so that breeders can make more informed breeding choices.

**5. Advertise and get the word out.** Coordinate information booths at health fairs, dog shows, and other dog events. Organize fundraisers. Distribute pamphlets and other brochures on Canine Epilepsy. You can design your own or distribute materials produced by your club's genetics committee. You can also design ads for your breed club's magazine or journal. Before I ran the first ad about Toby, no one had ever used a "poster dog" for epilepsy in our breed. After Toby's ad appeared in our breed's magazine and journal, and the disease had a name and a face, more people started talking about the problem and facing the reality of it.

**6. Start your own non-profit organization.** If this interests you, information and the applicable forms can be obtained from your Secretary of State. Simply fill out the forms, pay a small filing fee, and file your Articles of Organization with the Secretary of State. You can also find forms and instructions for applying for tax-exempt status from the IRS. Their informative publications even give examples of the wording you need to use in your Articles of Incorporation to have 501(c)(3) status. We started Toby's Foundation, Inc. to aid in the fight against canine epilepsy. Some other groups working to defeat Canine Epilepsy are The Australian Shepherd Health and Genetics Institute, [www.ashgi.org](http://www.ashgi.org) and The Canine Epilepsy Resource Center, [www.canine-epilepsy.com](http://www.canine-epilepsy.com)

**7. Support ongoing research.** The Canine Epilepsy Network (CEN) has links on its website for research being conducted by the Universities of Missouri and Minnesota. Visit the site at [www.canine-epilepsy.net](http://www.canine-epilepsy.net) and find out about the latest developments. The purpose of this research is to find a gene marker so that one day a screening test can be developed to identify carriers of the disease. You can also learn about how to donate blood samples for this DNA research and may even want to

organize a blood drive within your breed. Some of our local chapters organized blood drives for the research and through their efforts and others we tripled the amount of blood donations for our breed. The CEN site also has a list of breeds. If your breed is not involved, find out what that means. Perhaps the problem is not widespread in your breed yet or perhaps there is a lack of breeder or pet owner participation in gathering samples. Consider how you can get involved to make a difference.

### **Conclusion**

There are many ways you can join the fight against Canine Epilepsy. How involved you become is up to you. Admittedly, I am putting in far more time and energy than I ever imagined, but I am passionate about stopping this horrible disease. Until there is a screening test, the sharing of information and increasing awareness so that breeders can make better breeding decisions is the only way we have to manage this problem. There is still great concern about the number of carriers being used for breeding unknowingly. Until a screening test is developed, breeders can only assess the risk based on the most reliable information available to them. We need everyone to honestly and openly share information and donate DNA. This is critical to help save your breed.



**TOBY'S FOUNDATION, INC**

*Making Tracks to Defeat  
Canine Epilepsy*

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## **How to Join the Fight Against Canine Epilepsy**

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### **1. Contact your breed club to find out if a genetics committee has been established.**

If there is a genetics committee within your breed club, find out what they are doing to increase awareness about the problem of epilepsy and whom you can contact to get involved. Many clubs do have a genetics committee, but it may not be active or focusing on epilepsy.

### **2. Become an active member of your breed club.**

By joining your breed club you will be able to participate in voting, receive the club magazine, and will be eligible for special members' discounts on ad rates should you decide to draw attention to the problem of epilepsy through advertisements as we have done. In addition, you have more credibility as an official member because you show that you are invested in the breed. This is especially important if you are a pet owner. Pet owners make up the single largest group within the breed and breeders need them. Never let anyone dismiss your contributions or opinions if you are a pet owner, especially if