

## Topical Review

## Exocrine Pancreatic Insufficiency in Dogs and Cats: Online Support for Veterinarians and Owners

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## A B S T R A C T

Pet owners increasingly refer to online sources before, during, and after seeking veterinary advice for their pets. Although some online information is inaccurate or unhelpful, there is much useful material, and we believe much is to be gained by directing owners to online material that supports and complements veterinary advice. With regard to managing veterinary patients with exocrine pancreatic insufficiency (EPI), there is an excellent online community that not only offers moral support and practical advice, but also facilitates clinical research and fundraising. For genetic diseases like canine EPI that affect primarily young animals, but for which a decade or more of treatment can reasonably be expected, online support can greatly facilitate optimal lifelong management. In this article we provide some information that may be of value when veterinarians consider which web sites to recommend to their clients managing patients with EPI.

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Veterinarians are well aware that owners increasingly seek information about the health care of their pets over the Internet. Veterinarians themselves also increasingly look to the Internet to access the most current information. It is no surprise that information found online can be reliable or unreliable, and both veterinarians and owners may find it difficult or impossible to identify truly reliable information. Although many veterinarians are frustrated by some of the medical information that clients discover online, the Internet as a portal to the beliefs and opinions of others is not going to go away, and owners will continue to look things up online. In years past, many pet owners were perhaps satisfied with a gentle manner and informative veterinary care. However, many clients now want more. They expect thorough explanations and a variety of options with affordable pricing. If they discover that what their veterinarian told them is incomplete or they encounter contradictory information elsewhere, they often seek alternative veterinary guidance.

Most veterinarians know that exocrine pancreatic insufficiency (EPI) is a well-defined disease caused by inadequate pancreatic secretion of digestive enzymes into the small intestine. However, individual veterinarians usually encounter relatively few definitively diagnosed cases in the course of their entire professional careers. Consequently, although they know that EPI is now easily diagnosed by assay of serum trypsin-like immunoreactivity (TLI) in a single blood sample, their experience with long-term management of these patients, many of which will live with the disease for a decade or more, is often very limited. Owners need to appreciate that their veterinarians cannot be expected to be immediately aware of all the subtleties and complexities of the consequences of the disease, and that this awareness will probably evolve with experience over time, as will their own. Because canine and feline patients with EPI are often young at the time of diagnosis, they will require lifelong management of their malady, often at considerable expense and emotional cost. Rather than reacting negatively to information that an owner may randomly glean from the Internet, we believe that it makes more sense for veterinarians to be proactive and direct owners to reliable sources of online support, and to explain how to distinguish scientific

ically validated information from anecdotal opinion and put information from these sources into perspective. If clients are encouraged to discuss their Internet research findings with their veterinarians, they will gain a sense of what information is reliable and what is not, ask informed questions, and hopefully develop a deeper understanding of EPI. According to a 2011 Pew Research report, 8 out of 10 Internet users will search online for health-related information (<http://www.pewinternet.org/Reports/2011/HealthTopics/Part-2.aspx?view=all>). It appears inevitable that veterinarians will increasingly have to use the Internet in collaboration “with” the client, and that this may ultimately prove to be beneficial to both parties. Veterinarians have access to second opinions from specialists to which clients generally cannot connect, and this can complement online information freely available to all. The veterinarian may have to take time to explain why the specialist’s informed perspective should trump information gleaned from the Internet, but ultimately both the veterinarian and the owner will be best served if they work together to provide optimal management for each individual patient with EPI.

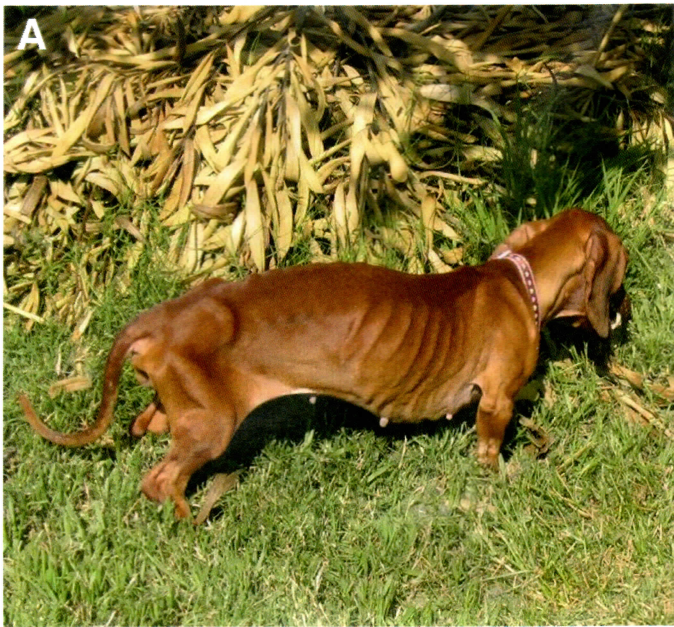
The purpose of this article is to direct veterinarians to the most reliable online information to which their clients will have free access so that they can be aware of it themselves. They can then guide owners to the most useful and current information available to lay people, hopefully thereby facilitating open and informed communication with the owner and access to the best treatment options for the patient.

**Online Resources Can Give Owners Hope That Their Pet with Severe Signs of EPI Has a Treatable Disease**

Despite the ready availability of assay of serum TLI, clients often do not seek veterinary advice until major clinical signs of weight loss and diarrhea are quite severe, and veterinarians historically have often not considered the diagnosis of EPI in the differential diagnosis of dogs with relatively mild weight loss. Thus, clinical signs can be quite extreme at the time of diagnosis (Fig. 1A).

Owners may be so distressed by the severity of the signs that they





**Figure 1.** (A) An estimated 5-year-old spayed female shorthaired Dachshund weighing 5.9 kg before treatment. (B) The same dog weighing 11.7 kg 6 months after treatment.

opt for euthanasia rather than treatment for their pet. Numerous online testimonials document often dramatic success stories that can encourage owners to consider treatment of even severely debilitated pets (Fig. 1B).

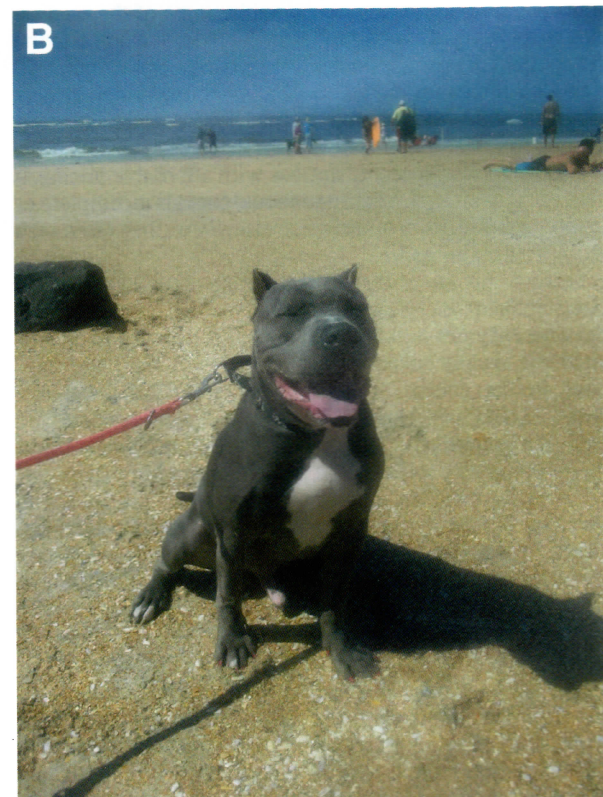
Online resources can educate otherwise misinformed members of the public, or other family members, that extreme clinical signs may reflect a treatable disease, and not cruelty or neglect.

Sometimes members of the public do not understand that an emaciated animal may be in such poor physical condition because of a medical condition and not abuse or neglect. Owners are sometimes accused of cruelty because they are treating an animal in such poor shape at all. Some family members may even have a difficult time understanding that a history of constant “accidents” in the house or untreatable behavioral or other problems may be caused by an illness, causing family dissension and getting rid of the dog (Fig. 2A), even though once diagnosed and treated appropriately EPI and all the “bad” behavior can be controlled very effectively (Fig. 2B). Online accounts detailing and illustrating these facts can be used to help educate the public about EPI, and that appropriate diagnosis and treatment usu-

ally lead to a very positive outcome even when clinical signs are initially quite distressing.

#### Online Resources Can Help Owners Have Reasonable Expectations of Their Veterinarian

Online information can help set realistic expectations for pet owners regarding what advice they can expect regarding EPI from their vets. Not all EPI cases treated with classical recommendations presented in textbooks display textbook responses, and there is no single, foolproof protocol for managing all patients with EPI. Veterinarians must be prepared to individualize treatment for each EPI patient—and this is where collaboration with a science-based Internet resource



**Figure 2.** (A) This emaciated male mixed-breed dog weighing only 16.7 kg was abandoned in a dumpster. (B) The same abandoned dog with body weight doubled after 3 months of treatment.



that includes recent and current actual experiences of owners of affected dogs can be very helpful.

Not only can an online support group's collective experience help owners navigate the day-to-day management of their pet's treatment, the support group can also educate the pet owner regarding specifically what to discuss and what questions to ask about EPI. Owners can discuss with one another online what observations and information may be most helpful to collect and share with their veterinarian, hopefully making the most of limited face-to-face time with the pet's health care provider. Conversely, the veterinarian may develop a better understanding of the intricacies of the daily management of these patients, be more aware of information not written in textbooks or journals, and therefore be better able to manage future patients with EPI. A good online resource, such as epi4dogs (<http://www.epi4dogs.com>), will hopefully help educate pet owners about the scientific method and evidence-based medicine. Whenever possible, they will refer to scientific evidence, or if there is a lack of evidence, remind owners that some statements are proven facts, fully supported by scientific evidence; others are logical deductions based on at least some known evidence; whereas others are merely opinions often based on skimpy anecdotal observation. A very important point that a good web site should stress is that the key to an EPI patient's well-being is for the owner to work together with a veterinarian, share what they have learned from other EPI owners and online sources, and be prepared to try to filter out the valid information that may help in the management of their pet. They can then feed these conclusions and experiences back into the online support group to minimize others having to reinvent the wheel.

#### **Online Resources Can Bring Together Both Scientific and Anecdotal Information to Enlighten Both Owners and Veterinarians and Optimize Treatment Response**

EPI is a lifelong condition that is completely manageable, but for optimal results, the owner and the veterinarian need to develop a symbiotic relationship. Online support provides a wonderful platform for gaining a better understanding comprising both the scientific research supporting veterinary advice and owners' day-to-day anecdotal management observations that are not published anywhere else. This can help facilitate a constructive and effective partnership resulting in optimal patient management.

A well-designed educational resource system such as <http://www.epi4dogs.com/> provides easy access to information about EPI that most lay people can understand. The web site further offers access to additional resources that may be useful to both veterinarians and pet owners. This site is frequently updated and refers to the most current relevant veterinary research studies. Overall it is a well-organized, user friendly blend of veterinary medical information and examples of owners' hands-on experience managing patients with EPI.

#### **Online Resources Give Access to a Support Group for Owners of Dogs and Cats with EPI**

In addition to the educational and informational resources, there is a 24-hour-a-day live support group (<http://www.epi4dogs.com/apps/forums/>) designed to provide a sense of community for EPI owners, and allows owners to share information and observations regarding experiences managing day-to-day issues. This free support feature is especially beneficial for those who may be experiencing some difficulty stabilizing the EPI patient in the days to weeks after diagnosis, or in managing a setback in patients that have been stable for years. Considerable patience over several weeks or even months may be required to establish the best combination of therapies for individual pets, and online contacts can provide moral support to owners during this sometimes frustrating period. This support group is an open forum; no application or registration is required, and immediate activa-

tion is granted. This group is not sponsored by any entity for financial gain or product promotion. Any specific product recommendation by members is based solely on their personal experience. A group of 10 volunteers monitor the open online support communication in an effort to ensure proper and respectful communication at all times. When exploring the online support group it becomes very evident from the discussions that the severity and spectrum of clinical signs of EPI often vary greatly from one animal to another. Sometimes this just reflects variable delay in establishing the diagnosis of EPI, but as discussed elsewhere in this volume, some patients require additional therapeutic interventions and patience is required to establish what is needed for optimal management of each individual. Support group discussions help some owners work through this sometimes difficult and frustrating process, and help provide some basis for prioritizing different potential therapeutic options.

#### **Online Informational Topics at <http://www.epi4dogs.com>**

- Overview: a concise but thorough illustrated explanation, geared toward the pet owner, of what EPI is, and what can (or cannot) be expected. This is a great place for veterinarians to refer their clients once a diagnosis of EPI has been made.
- Testing for EPI: how to properly prepare a patient for a serum TLI test and how to interpret the results. Specialist laboratories such as the Gastrointestinal Laboratory at Texas A&M University (<http://www.cvm.tamu.edu/gilab>) are also listed so that clients are aware of additional levels of support that they may wish their primary care veterinarian to consult with once a diagnosis has been made.
- Pancreatic extract for enzyme replacement: many preparations are available and the site gives a comprehensive list of a variety of appropriate preparations and their potencies that may be considered for enzyme replacement. Most importantly, the tremendous cost savings that can be realized by bulk purchase of generic pancreatic extract available from EnzymeDiane (<http://www.enzymediane.com>) is noted. These extracts are comparable with those used by many prescription preparations and are available more directly to pet owners. Given the relatively high cost of treatment, this online information about effective but affordable enzyme preparations is sometimes pivotal in helping owners to decide whether to treat the animal. This site also lists sources of pancreatic extracts for owners internationally who do not have access to pancreatic extracts prepared in the United States, as well as information on where to obtain raw pancreas, how to prepare and preserve it, how much to feed, and the possible benefits or pitfalls of using raw pancreas. The online support group can help guide owners who are having difficulty achieving optimal results after enzyme supplementation. Often it is simply a matter of altering the enzyme preparation technique (mixing, wetting the food); other times correction of minor miscommunication between owner and veterinarian is all that is required.
- Diet: there are general dietary guidelines for feeding dogs with EPI, but within these guidelines there often is quite a degree of variability in owners' perceptions of their pet's response to different diets. Online information offers a multitude of possible dietary options and a variety of preparation techniques that owners may elect to follow on a trial-and-error basis to see what works best for their pet. Because diet can be important in managing EPI optimally, it is very helpful when pet owners can share their experiences with one another. The site lists many brand-name over-the-counter and prescription foods that have worked well for many EPI patients, and owners can read the opinions of many others regarding the pros and cons of different options. They also can help one another when one owner might become discouraged because the product they are using works for other dogs but not their own. One of the biggest advantages of the online resource and support group is that owners help each other navigate day-to-day management when things do



not go according to plan, especially with regards to diet. Sometimes simple common sense recommendations such as buying small 1- to 2-week supplies of trial diets rather than big bags of food can save considerable expense and can make owners cope more effectively with trying to optimize response to treatment or to deal with minor setbacks. Although mostly anecdotal, sometimes simple measures such as changing the brand of food, changing ingredients in home-made diets, or preparing the food a little differently are often perceived to make a huge difference. Other often apparently effective recommendations have included added coconut oil or fish oil to the meal to help with poor coat condition, addition of fiber such as canned pumpkin to improve stool quality, and adding grated parmesan cheese or a sardine to enhance appetite in those unwilling to eat food mixed with pancreatic extract. Sharing experiences and concerns online often allows rapid and often immediate responses from others who either are dealing with or have dealt with the same issues.

- Cobalamin (vitamin B12): to assist veterinarians unfamiliar with serum cobalamin (vitamin B12) assays, there is information on how and where to have the cobalamin (vitamin B12) assays done. Reference is made to current cobalamin (vitamin B12) research studies and suggested dosage requirements. To enhance the pet owner's understanding there is an explanation of how cobalamin (vitamin B12) is absorbed and the role of intrinsic factor, and information about the function of cobalamin (vitamin B12), folate, and some other vitamins and trace elements. When a patient is receiving enzyme replacement but not yet thriving, or when a patient displays inappetence, pet owners are encouraged to speak to their vet about evaluating serum cobalamin (vitamin B12) concentrations. When a formerly well-regulated patient starts to exhibit clinical signs again, pet owners are encouraged to talk to their vets about new potential problems and also consider reevaluation of serum cobalamin (vitamin B12) and folate concentrations.
- Small intestinal dysbiosis (SID) (also known as small intestinal bacterial overgrowth): The role of SID in clinical signs of dogs with EPI is controversial, in large part because of the difficulty of performing scientific studies in this area and the consequent paucity of knowledge. There is a widespread sentiment among veterinary gastroenterologists, however, that SID is very common in dogs with EPI and persists after enzyme replacement. When it causes clinical signs, when it should be treated, with what, and for how long are all open to debate, as are the short-term and long-term efficacies of the available potential therapies. There are few clinical studies of the pros and cons of antibiotics, probiotics, and prebiotics. Experiences of owners after treating their dogs with potential therapies are cited on the support group in an effort to help others understand how idiosyncratic responses of individual dogs can be, and that much therapy is based on trial and error in each individual. Currently, many owners find tylosin to be helpful in treating residual diarrhea, and after weeks of treatment may have been able to transition gradually to a combination of probiotic and/or prebiotic without recurrence of diarrhea.
- Concurrent conditions: also available at the online web site is a section listing other medical conditions and abnormalities that owners may also be trying to manage concurrently with EPI, including diabetes mellitus, idiopathic inflammatory bowel disease, elevated liver enzymes, urinary tract infections, seizures, etc. Although these other conditions are unrelated to EPI, sometimes appropriate treatment may conflict with optimal management of EPI and extra caution should be exercised (Fig. 3A). Online discussion of these issues can facilitate owners making rational and hopefully evidence-based decisions when none of the options is ideal (Fig. 3B).
- "Before" and "after" photos: there are photographs online of EPI patients belonging to support group and other online members. These photos help encourage owners of newly diagnosed EPI pa-



**Figure 3.** (A) A German Shepherd family pet in October 2010 at 23.4 kg having difficulty managing EPI + inflammatory bowel disease. (B) The same German Shepherd 1 year later in October 2011 at 31.5 kg; stabilization was realized via online "individualized" support with diet and antibiotic modifications.

tients that there is hope, and that EPI can usually be treated effectively. However, the reality is that there are no guarantees and that a small percentage of EPI patients never fully recover. However, hopefully owners of such animals will be assured that they have tried everything that might help.

- Not just German Shepherd Dogs: there is a regularly updated listing of the numbers of all breeds of dogs diagnosed with EPI to educate the public that this is not a disease that affects just German Shepherd Dogs.
- Research: this section is primarily focused on providing current information regarding progress on genetic research currently being conducted at Clemson University, and provides links to updates at Clemson Canine Genetics (<http://www.clemsoncaninegenetics.com>).
- Recommended Vets: solely compiled by grateful EPI owners is a list of personal recommendations of vets that EPI caretakers were very pleased with and that they would like to share with others.



- Video Gallery: a variety of videos are presented by EPI owners, some simply entertaining, but also there are “how-to” videos that visually show owners useful demonstrations such as how to administer a cobalamin injection, how to supplement meals with powdered pancreatic extract or raw pancreas, and what improvements in stool quality should be expected in response to optimal treatment measures.
- Nonscientific sections: beyond provision of scientific information, the site provides emotional support sections such as (to name a few) the Memorial page, which helps give comfort to those who have lost pets to EPI, or the Chunky Monkey Club page, which started as a lighthearted, fun page but where posted bragging rights have become a coveted achievement.

### Online Access to Affordable Pancreatic Extract Preparations

As mentioned earlier, there is an excellent and reputable resource of generic enzymes available at very reasonable cost because of bulk purchasing by Enzyme Diane (<http://www.enzymediane.com>). This web site offers a wealth of information regarding US food-grade pancreatic porcine and beef enzyme extracts that is well worth reading. These generic enzymes are processed according to strict United States Pharmacopeial Convention (USP) guidelines in a plant located in the United States, and the glands are sourced only from the United States Department of Agriculture-inspected facilities. The site explains what pancreatic enzymes are, what they do, and how they should (and should not) be handled.

- The web store: lists which pancreatin products are available, if there are any backorders on certain products and why, estimated time of released shipments, various grades of enzymes, such as 6× or 8×, various types of enzymes such as powder or granular, and different enzyme sources such as US-sourced or European-sourced enzymes depending on what a customer might prefer. Varying amounts of enzymes may be purchased to best suit the customer's needs and accommodate any financial constraints they might have. Special packaging is also available for shipping in hot environments.
- An enzyme comparison chart allows comparison of different products with regard to factors such as USP units of each enzyme, details of the manufacturer, and any additives such as vitamins A, D, and E, and associated volumes and costs.

- A material safety data sheet is posted on the web site so that customers can see the US laboratory from which the enzymes are obtained along with their contact information. A certified US material safety data sheet, from required testing performed on every batch of extract, is included with every package of enzymes sold.
- Estimated costs of managing EPI are listed to give the pet owner an idea of what the expense might be based on the amount of food, type of diet, amount of enzymes, and possible supplementation of cobalamin (vitamin B12) and antibiotics.

### Accessing Specialist Veterinary Gastroenterology Laboratory Testing and Advanced Specialist Expertise

The premier veterinary gastrointestinal laboratory at Texas A&M University, the Gastrointestinal Laboratory (<http://www.vetmed.tamu.edu/gilab>), is another excellent web site to visit or consult with in regards to EPI. Although they provide numerous services, those of specific relevance to EPI include assay of serum TLI, including a unique test for use in cats, and serum cobalamin (vitamin B12) testing for small intestinal function. These tests were pioneered by this laboratory and they have been working in this field for more than 30 years and have more collective experience in veterinary gastroenterology than any other laboratory. Most uniquely, as a prelude or follow-up to testing, when requested they can arrange for veterinarians to have a consultation with a board-certified veterinary internist with special interest and expertise in companion animal gastroenterology, a service for which there is no additional charge.

### EPI Registries for Clinical Research Projects

Online support groups provide access to a gravely underused audience that is more than willing to participate in clinical research projects. Registered membership for <http://www.epi4dogs.com> is currently close to 1000 and for <http://www.enzymediane.com>, it is over 3000. About 70% of members participate when a request is sent out that requires participation. Both of these sites have collaborated in setting up a current EPI registry to assist with possible future veterinary research projects.

In 2010, an informal survey of over 2600 patients identified online was conducted regarding breeds afflicted with EPI. The survey produced results very similar to those obtained by other laboratories, in

**Table 1**

Aspects of EPI addressed by the 3 major specialist web sites to which pet owners and veterinarians have free access

	<a href="http://www.epi4dogs.com">http://www.epi4dogs.com</a>	<a href="http://www.enzymediane.com">http://www.enzymediane.com</a>	<a href="http://vetmed.tamu.edu/gilab">http://vetmed.tamu.edu/gilab</a>
Free access	X	X	X
Free vet consultation			X
Open discussion group	X		
EPI overview	X		
EPI awareness efforts	X	X	
TLI testing and information	X		X
Cobalamin (vitamin B12) testing and information	X		X
Small intestinal bacterial overgrowth information	X		
Diet information	X	X	
EPI cost-savings management techniques	X		
Enzyme information	X	X	
Enzyme comparison		X	
EPI costs		X	
Enzyme material safety information		X	
Breeds diagnosed with EPI	X	X	
Concurrent conditions information	X		X
Fundraising	X	X	X
EPI products	X	X	
Research updates	X		X
Current research studies			X
Before and after EPI photos	X		
Specialist consultation			X
Recommended veterinarians	X		
EPI registry	X	X	



that approximately half of the affected dogs were not German Shepherd Dogs. Two years later, a repeat online survey indicated that a smaller proportion of affected dogs were German Shepherd Dogs, with a majority of patients being of other breeds. Online registries have huge potential to facilitate future clinical studies of EPI, and the authors of this article will be happy to promote such endeavors.

### **EPI Awareness and Fundraising Efforts**

The online EPI community has evolved into such an effective presence that it has successfully spear-headed multiple "EPI awareness" projects, such as an informative educational brochure that was distributed to over 5000 veterinarians in the United States. This brochure has become so successful that it has since been translated and distributed in other countries. The web site <http://epi4dogs.com> won the October 2010 Pepsi Challenge in the Health Category (<http://www.refresheverything.com>) solely from the efforts of its online networking membership to promote EPI awareness and raise money for EPI genetic research. Information from <http://www.epi4dogs.com/> has been translated and shared in numerous other countries and continents including France, Thailand, Israel, China, South America, Slovenia, Spain, Greece, England, Australia, Scotland, and Canada. The online EPI support community has been represented at meetings of the

American Veterinarian Medical Association and the American College of Veterinarian Internal Medicine. Drives to collect blood samples from German Shepherd Dogs and other canine breeds for genetics research have been successfully concluded in record time because of the camaraderie and cooperation of the online EPI support group. Fundraising efforts are hosted annually to raise money to support the EPI genetic research currently being conducted at Clemson University.

### **Conclusion**

Although there are downsides to clients having access to online information, some of which is certainly unreliable, we believe that there are huge potential benefits to be gained by pet owners having access to accurate and up-to-date online information. (Table 1). We suggest that veterinarians provide guidance to finding the best online information. Furthermore, the online community is very open to working with veterinarians to promote research studies on EPI, and to help raise financial support for such studies. There is a tremendous public thirst for reliable information about EPI, and online resources can play a major positive role in helping veterinarians and owners of affected animals work together to provide the best patient management possible.