

Exploring the Bond

Genetic counseling for cat and dog owners and breeders—managing the emotional impact

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The Feline and Canine Genome Projects were established to map and identify the genes that make up the cat and dog. Genetic maps that cover most of the feline and canine genomes have been generated^{1,2} and form a basis for understanding the precise DNA sequence responsible for appearance, behavior, health, and disease. Through this process, the exact gene(s) responsible for the 300 known genetic diseases of the dog³ and the 150 inherited abnormalities of the cat⁴ will be defined. Many disorders found in purebred dog and cat populations are brought to the attention of veterinarians by dedicated breeders.

In humans, there are more than 4,000 inherited conditions that have been diagnosed by syndrome recognition and special laboratory tests such as karyotyping, biochemical analyses, and DNA sequencing.⁴ At present, there are more than 500 genetic diseases that can be diagnosed by analyzing DNA.⁵ This list is rapidly increasing, and it is highly likely that diagnostic DNA tests for all known common monogenic recessive conditions, age-onset dominant conditions, and some polygenic conditions will become available within the next 2 decades. Because mammalian DNA is highly homologous, it is plausible that a number of these tests will be applicable to similarly affected cat and dog populations. Indeed, the disease-causing mutations for feline gangliosidosis⁶ and mucopolysaccharidosis type VI⁷ as well as canine hemophilia A⁸ have been identified, using valuable clues provided by DNA studies in humans and mice.

In human medicine, medical geneticists and trained professionals offer counseling, in addition to diagnostic tests, to help individuals and families understand the diagnosis of a heritable disease and approaches to its management. These professionals help those affected comprehend how heredity has contributed to the disorder, understand the options for dealing with recurrence, and choose the most appropriate course of action considering the patient's risk and goals.⁹ Given the close attachment that dog and cat owners have to their pets and the subsequent involve-

ment of the veterinary health care team,^{10,11} veterinarians and their human clients have an urgent and increasing need to understand molecular genetics and its impact. This includes a basic understanding of DNA structure, genes, chromosomes, meiotic recombination, and the ability to define the precise genetic makeup of an individual by use of molecular techniques such as **polymerase chain reaction (PCR)** and Southern blot analysis.¹² These concepts and their relevance to improving the breeding of domestic animals have been reviewed in the literature.^{13,14}

Veterinary professionals must not only provide knowledge-based diagnosis and treatment of genetic problems,¹⁵ but they must also be able to explain the ramifications of the diagnosis and be mindful of the considerable distress and grief that this news may bring to owners and breeders of a valued breeding animal. Not only will a decision need to be made regarding management of the animal's reproductive future,¹⁵ but in some inherited conditions, such as feline **polycystic kidney disease (PKD)**¹⁶ or hypertrophic cardiomyopathy,¹⁷ the identification of a disease-causing mutation may signal an early death in an otherwise healthy animal.

Recent application of a predictive clinical test for adult-onset feline PKD in Persian cats has yielded positive results for approximately 36% of 5,773 cats tested worldwide.¹⁸ Breeders' and owners' emotional reactions ranged from elation, in the case of negative results, to heartbreak when results of a cat's test were positive. Their responses ranged from denial and withdrawal to proactive approaches to prevention. Some breeders have publicly listed their cats' results and encouraged others to have their cats tested, as this may assist in making medical treatment decisions. Others have offered to provide affected catteries with cats whose test results were negative in an effort to help these catteries restock. In addition, many breeders have participated in educational seminars and actively support fund raising to develop a DNA test for PKD.

The array of emotions and reactions observed resembles those seen in human patients and their families undergoing genetic counseling at the **Victorian Clinical Genetics Service (VCGS)**, which provides services for the estimated 5 million people of Victoria and Tasmania. The VCGS has counseled more than 25,000 families at risk for genetic diseases, and several counselors (MS, RT, and Sue Mansie) have identified strategies that may help veterinarians, breeders, and

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owners deal with results of predictive tests for inherited conditions in dogs and cats. There are several publications in the literature that describe genetic counseling in veterinary practice,^{15,19,20} but these offer little information that will assist breeders and owners in coping with the emotional turmoil associated with predictive screening of their animals. This report describes some successful strategies employed by genetic counselors that may be of use to veterinarians and breed fanciers.

Counseling Strategies

First and foremost, genetic counseling demands confidentiality.²¹ It also requires giving and receiving accurate information in a manner that allows clients to make their own decisions about any course of action.²² Initially, clients will need to know the cost and possible outcome of genetic testing, what treatment(s) is (are) available if positive results are obtained, and how results will be conveyed (eg, in person, by telephone, or by letter).²³

Besides knowing what genetic tests are currently available, veterinarians must be skilled at asking open-ended questions and listening actively to their clients' answers without assumption or prejudice. Dynamic issues veterinarians need to raise include whether anyone else should be present during these discussions (eg, other family members who may be affected by the results) and whether the client will permit their animal's results to be included in computer databases such as the Feline and Canine Genetic Disease Information Systems.²⁴ Dog and cat owners may not understand their animal's condition or they may possess considerable knowledge, because such information is readily obtainable via print or electronic media. Veterinarians need to ensure that their client's understanding of their animal's condition is accurate. Care must be exercised in estimating risk factors, and prognosis must be considered when formulating advice for owners and breeders.

The time between initial contact and availability of test results can be important, because this is an opportunity for clients to consider the information they have and may receive and to think through its likely consequences.²⁵ For human families, processing this information often leads to a cascade of emotional decision making, and clients may benefit from active coping strategies. For example, people at risk for autosomal dominant age-onset conditions such as Huntington's Disease have been greatly aided during the testing process by keeping a "journal of feelings." In this journal, which may be in written or pictorial format, people undergoing testing imagine and document how life would change if their test results were negative or positive. This activity has helped numerous individuals work through important issues before test results are received and has helped them contain feelings of anxiety.²³ This strategy may also help animal owners better manage their concerns. Veterinarians may assist owners in making decisions by indicating to them what decisions need to be made immediately and what decisions can be deferred to a later date.

Ideally, critical information should be conveyed in a private area, without interruptions (eg, no telephone

calls should be accepted, and pagers should be turned off). The veterinarian must be able to tolerate and acknowledge strong expressions of emotion and, if necessary, prepare clients with phrases such as "I'm afraid I have some bad news." People receiving positive genetic testing results may be shocked and not immediately comprehend this information.²⁵ In some instances, the owner may not believe the results, because the animal looks healthy. It may be necessary to authenticate the likelihood of a genetic problem by showing pictures and describing affected animals to the client. Outcome(s) may need to be reiterated, and follow-up should include a written letter attesting to the results obtained. Veterinarians should be available, as needed, for further consultation or should refer their clients to another appropriately trained member of the veterinary team or a professional counselor.

In addition, clients may benefit from contact with a support person,^{25,26} such as another breeder who has been through the testing process. It must be understood, however, that many breeders exhibit their animals in shows on a regular basis, and some individuals may feel it inappropriate to discuss a genetic health problem in their animals' bloodlines with another breeder. In human genetic counseling, there has been a rapid increase in the number of support groups for people and parents of children with inherited conditions. These groups establish a partnership between those affected and professionals and facilitate contact with other individuals who, because they are also affected, instantly understand shared concerns and experiences. A good example of such support is the Keeshond Club in the United Kingdom, which has formed a mentor group for new breeders in an effort to reduce inherited epilepsy in this breed.²⁰ At the Feline Control Council in Victoria, we have encouraged breeders who need additional support to seek out experienced breeders who do not have a potential conflict of interest with the breed at risk.

The close link between genetics, breeding, and the ability to show animals deserves special consideration. Most feline fancy governing bodies allow neutered pedigreed cats to be exhibited in a designated category, whereas the converse policy exists for many show dogs. This means that if genetic testing identifies a successful show dog as a carrier of a genetic condition, and neutering is recommended as a result, it will probably signal an end to the dog's show career. Breeders and owners who own such dogs may experience "loss of dream" and suffer grief.

Dealing with Loss and Grief

Issues related to human-animal relationships²⁷ and counseling grieving pet owners have been addressed in the literature²⁸ and in some veterinary medical curricula.^b Given that predictive screening test results have the potential to be distressing for some breeders who feel that many years of work may have been lost in a moment, veterinarians may find themselves confronted with breeders experiencing sadness and guilt at having bred and sold animals with possible genetic defects.

One reaction that may be observed among breeders is disenfranchised grief. This develops when grief

cannot be publicly expressed or when the grieving process is not allowed to progress through its normal stages.²⁹ In this situation, emotional responses such as guilt may be heightened.³⁰ Some breeders may feel isolated if they believe they are unable to publicly discuss lifestyle changes in their animals that are associated with potential or real genetic problems. This may take place when a dog or cat is still alive but can no longer participate in planned breeding programs or show exhibitions. Breeders may be confronted with the ethical dilemma of what to do with such animals and may not wish to discuss options such as euthanasia for fear of reprisal. They may also be aware of the perception that genetic health problems in pedigreed cats and dogs are directly related to having to conform to set breed standards and policies established by feline and canine breed clubs.³¹ Inadvertently, striving to meet these criteria has led to a permanent reduction in individual dog breed gene pools and an increase in genetic problems.³² To support breeders who are experiencing disenfranchised grief, veterinarians need to be alert to breeders' feelings of isolation and guilt and be sensitive in deciding what to tell to whom and when. Many grief counselors already have experience with counseling pet owners undergoing disenfranchised grief, because pet owners' intense feelings associated with the loss of their companion animals may not be understood by the community at large.³³

Veterinarians need to recognize that grief and loss as a consequence of genetic testing may be further compounded and complicated by the number of animals involved and associated financial costs. Short term, there is the cost of screening the remaining animals and potential loss of income from stud fees and kitten and puppy sales. In addition, animals may have shortened lifespans and require veterinary care more frequently.

Possible Reactions Encountered During Counseling

Some owners may express anger and resentment toward breeders from whom they have purchased affected stock. Others may displace their anger and blame their veterinarians. Still others may dismiss the findings of predictive testing by claiming incompetence on the part of the veterinarian (rather than addressing their emotions)²⁵ or may accept the findings but dismiss the implications, because they find them too difficult to deal with.

Although all these reactions can be a challenge for veterinarians, dealing with dismissive reactions can be particularly difficult. Veterinarians' attempts to convince owners and breeders that there is a potential problem may be met with scorn; eventually objectivity may suffer, and dismissal may become mutual. Remaining neutral and emphasizing the client's autonomy may allow discussion of care and treatment needs that the client acknowledges while permitting differences to be gently explored. Clients who accept findings but are unable to face their implications often fail to keep appointments. Veterinarians must be direct when giving advice to these clients and arranging tests.²⁵ Follow-up phone calls are particularly important.

Not surprisingly, some owners and breeders appear quite concerned about how other owners and breeders will react to their having a genetic health problem in their animal or breeding line. There may also be some angst as to whose responsibility it is to inform others about the likelihood of a genetic problem in their animals. Veterinarians may assist by providing clients with appropriate terms to use to describe the problem. This provides the client with a framework for disseminating information and gives the veterinarian an opportunity to point out the advantages of sharing information in an open manner. Occasionally, a client may prefer that the veterinarian transmit this information to interested parties. This should only be done with client consent and in the client's presence.³⁴

Deferral strategies may be adopted by breeders whose animals have similar genetic bloodlines to animals whose test results are positive. These breeders may acknowledge a problem in the breed but remain reluctant to involve their animals in testing programs. Some owners have questioned how to get breeders to participate in feline and canine genetic screening programs, and the unwillingness of a particular breeder to participate may cause distress for the owner of an affected animal. This distress can be overcome, in part, by reminding owners that people react to disturbing news in different ways, and sometimes a little time, space, education, and example are needed. Concerned owners should be encouraged to concentrate their energy on working with breeders, breed fancy governing bodies, veterinary health care teams, geneticists, and scientists who are willing to participate in predictive screening programs.

Conclusions

Predictive genetic screening for dogs and cats has great potential for improving our understanding of inherited diseases and refining approaches to their treatment. However, because positive results of screening usually carry negative consequences for the animal(s), their owners, and breeders, veterinarians must be prepared to provide emotional support as well as up-to-date medical information and advice. Angst can be reduced by providing accurate information in an environment of mutual trust. This will enable owners and breeders to make informed decisions that are in the best interest of their animals, their animals' offspring, and themselves.

^aGiger U, Seybold C, Knighton E. Feline genetic disease information system (abstr), in *Proceedings. First Int Genet Dis Conf*, 1998.

^bAdams CL, Conlon P. Professional competencies: addressing human-relations issues for entry-level veterinarians. *J Vet Med Educ* 2000;in press.

References

1. Lyons LA, Laughlin TF, Copeland NG, et al. Comparative anchor tagged sequences (CATS) for integrative mapping of mammalian genomes. *Nat Genet* 1997;15:47-56.
2. Mellersh CS, Langston AA, Acland GM, et al. A linkage map of the canine genome. *Genomics* 1997;46:326-336.
3. News and Reports. Companion animals. Hereditary diseases in dogs: working towards a common goal. *Vet Rec* 1997;140:490-491.

4. Online Mendelian Inheritance in Man Database. Available at: <http://www3.ncbi.nlm.nih.gov/omim>. Accessed February 1999.
5. Index of genetic testing laboratories by disease. *Genetic Testing* 1998;2:135–168.
6. Muldoon LL, Neuwelt EA, Pagel MA, et al. Characterization of the molecular defect in a feline model for type II GM2-gangliosidosis (Sandhoff disease). *Am J Pathol* 1994;144:1109–1118.
7. Crawley AC, Yogalingam G, Muller VJ, et al. Two mutations within a feline mucopolysaccharidosis type VI colony cause three different clinical phenotypes. *J Clin Invest* 1998;101:109–119.
8. Clark P, Bowden DK, Parry BW. Studies to detect carriers of haemophilia A in German shepherd dogs using diagnostic DNA polymorphisms in the human factor VIII gene. *Vet Rec* 1997;153:71–74.
9. Fraser FC. Genetic Counseling. *Am J Hum Genet* 1974;26:636–659.
10. Becker M. Celebrating the relationship between people, pets, and their veterinarians. *J Am Vet Med Assoc* 1997;210:1126–1129.
11. Stutts JC. Exploring the Bond. Veterinarians and their human clients. *J Am Vet Med Assoc* 1997;210:1742–1744.
12. Williamson B. Medical ethics, teaching and the new genetics. *J Med Ethics* 1996;22:325–326.
13. Buitkamp J, Epplen JT. Modern genome research and DNA diagnostics in domestic animals in light of classical breeding techniques. *Electrophoresis* 1996;17:1–11.
14. Georges M, Andersson L. Livestock genomics comes of age. *Genome Research* 1996;6:907–921.
15. McNeil MT, Ponce de Leon FA. The role of veterinarian in genetic counseling. *Probl Vet Med* 1994;471–490.
16. Biller DS, DiBartola SP, Eaton KA, et al. Inheritance of polycystic kidney disease in Persian cats. *J Hered* 1996;87:1–5.
17. Hedden V. Knowledge about human heart disease spurs scientists to study cats. *Cat Fanciers Almanac* 1998;14:61.
18. PKD summary page. USA Persians. Available at: http://www.indyweb.net/~lucky/stats_usa.html. Accessed January 1999.
19. Bowling AT. Counseling for genetic diseases of horses. *Vet Clin North Am Large Anim Pract* 1980;2:377–389.
20. Hall SJG, Wallace ME. Canine epilepsy: a genetic counseling programme for keeshonds. *Vet Rec* 1996;138:358–360.
21. Kessler S. Psychological aspects of genetic counseling. XII. More on counseling skills. *Genet Couns* 1980;7:263–278.
22. White MT. Respect for autonomy in genetic counseling: an analysis and a proposal. *J Genet Couns* 1997;6:297–314.
23. Mansie S, Sheffield L, Forrest S. Selection for presymptomatic testing for Huntington's disease—who decides? A reply from the Victorian Clinical Genetics Service, Melbourne, Australia. *Hum Med Genet* 1996;33:1051–1052.
24. Patterson DF, Aguirre GA, Fyfe JC, et al. Canine genetic disease information system. *Pure-bred Dogs/American Kennel Club Gazette* 1987;104:58–61.
25. Lubinsky M. Bearing bad news: dealing with the mimics of denial. *Hum Genet Couns* 1994;3:5–13.
26. Munro EA, Manthei RJ, Small JJ. Beginning a counseling relationship. In: *Counseling—a skills approach*. Auckland: Methuen Publications NZ Ltd, 1983;30–49.
27. Lawrence EA. A veterinarian's involvement in the field of human-animal relationships(lett). *J Am Vet Med Assoc* 1988;192:6–7.
28. Antelyes J. The human side of veterinary medicine. The veterinarian as counselor. *J Am Vet Med Assoc* 1989;195:732–734.
29. Doka KJ. Disenfranchised grief. In: Doka KJ, ed. *Disenfranchised grief: recognizing hidden sorrow*. New York: Simon and Schuster, 1989;3.
30. Meagher DK. The counselor and the disenfranchised griever In: Doka KJ, ed. *Disenfranchised grief: recognizing hidden sorrow*. New York: Simon and Schuster, 1989;313.
31. Burke D. Letter received in answer. *Feline Focus* 1998;26:13.
32. Ubbink GJ, van de Broek J, Hazewinkel HA, et al. Cluster analysis of the genetic heterogeneity and disease distributions in purebred dog populations. *Vet Rec* 1998;28:209–213.
33. Stewart CS, Thrush JC, Paulus G. Disenfranchised bereavement and loss of a companion animal: implications for caring communities. In: Doka KJ, ed. *Disenfranchised grief: recognizing hidden sorrow*. New York: Simon and Schuster, 1989;47.
34. Fullwood D, Cronin P. Facing the crowd: managing other people's insensitivities to your disabled child. *RVIB* 1989;16:97–107.