

LIVING with Pug Dog Encephalitis: Payton's Story



Our pug, Payton, is a miracle and the toughest creature we've ever met. In 2006, at only 3 ½ years old, she was diagnosed with Pug Dog Encephalitis (PDE). It is a rare and little understood disease of the brain that causes seizures and is usually fatal in only days or weeks. But she has been thriving for almost 6 years now despite this horrible condition. It hasn't always been easy, but with lots of love, sacrifices, and prayer, she leads the most wonderful life! Because there is so little information available and no hope, we started a blog, Pugnacious P...tales of Payton the Pug (<http://pugnaciousp.blogspot.com/>), to raise awareness of PDE, share our experiences, and spread hope. And now the great people behind the Milwaukee Pug Fest have allowed us to reach even more pug lovers today in honor of Payton's **9th Birthday** on March 21st!

To get started, I want to provide some general information about the disease for those of you that aren't familiar with it (I am paraphrasing from on-line resources)...

PDE is a unique form of brain inflammation affecting pugs. Clinically, the disease is described as a necrotizing meningoencephalitis. This means that the brain and the layer of tissues surrounding the brain are abnormally inflamed. The term "necrotizing" describes the clinical way in which portions of the brain are literally dying.

The cause of the condition is unknown. Although infectious disorders are known to cause encephalitis, infection is apparently not the cause of PDE. Recent studies suggest that an abnormal response by the body's immune system may play a role in the development of the disorder. It is believed to be a genetic condition, as littermates and closely related dogs are often affected. The most current research indicates that susceptibility is associated with the dog leukocyte antigen region of dog chromosome 12. [Ok, that was a bit too technical for me, so I hope I haven't lost anyone.] Dr. Kimberly Greer (<http://www.iue.edu/nsm/research/greer/>) has helped to develop a UC Davis test that will determine risk for developing PDE in Pug Dogs and for selecting mates that will produce puppies that are at decreased risk, but there is still no definitive diagnostic test and only analysis of the brain after death can confirm suspicions of the disease.

Symptoms of PDE might include: seizures, pressing of the head against a wall or furniture, a staggering walk, abnormal gait, walking in circles, apparent blindness, lethargy, depression, staring off into space,

neck pain or stiff neck, and intermittent screaming. It is very important to note that when Payton first got sick, she did not display the entire classic profile for PDE so do not assume that the list of symptoms is accurate or complete. However, over the course of many years, she has displayed most of them at one time or another.

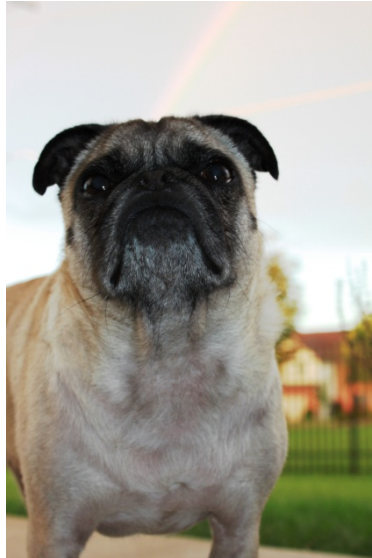
Payton's story started with a simple ear twitch (later we found out that these pinpoint muscle spasms are called focal seizures) that progressed to a full body seizure the next day and a frantic car ride to our local vet. To read more about how Payton's battle with PDE began, please see the Diagnosis post (<http://pugnaciousp.blogspot.com/2011/05/paytons-battle-with-pdediagnosis.html>) on our blog. This disease can progress so rapidly that I can't express how important it is to take immediate action after noticing any suspicious symptoms. We were so blessed that our local vet knew we needed to take act fast and made arrangements for us to see a specialist the same day. We eventually ended up in the hands of Payton's miracle worker, Dr. Michael Podell (http://michaelpodelldvm.com/Home_Page.html), who has a neurology practice in Chicago IL. He used MRI and spinal tap tests to diagnose PDE (although not definitive, they are the best tools available now), and he has prescribed a treatment regimen that has worked for Payton. It is a very long (and if I'm being totally honest, expensive) list of mostly human grade drugs that can be found categorized in the Treatment post (<http://pugnaciousp.blogspot.com/2011/05/paytons-battle-with-pdetreatment.html>) on our blog. There was no guarantee that Payton would take to the medicines, and it was slow going at first as her little body adjusted to such powerful pills. As destructive as the disease is, the medication that helps can have some bad side effects. So many drugs, at such high levels, can take its toll on the rest of her body. The key is to finding the lowest levels of drugs to minimize the impact on her body's other organs (specifically the liver) yet keep away the disease in her brain. If the PDE doesn't progress beyond treatment, then eventually the medications (or at least some of them) will cause organ failure. Such a tricky balancing act!

At the beginning the disease was isolated to the right side of her brain, which means that her left side is affected. However, approximately 2 years ago, Dr. Podell had to perform another MRI because Payton was having unrelated back pain. So he took the opportunity to take another look at her brain. The recent MRI showed that the PDE has spread to both sides of her brain. We hope that this rare 2nd look at a pug living with PDE will aid in the research. When Payton's battle is over, we plan on donating her body and records to Dr. Greer's research so that her fight can benefit others.

Along the way Payton has had about 3 relapses where the disease seemed to over-power the treatment, but adding new drugs and adjusting dosages have been able to keep it at bay to date. She has had to deal with her fair share of side effects, both from the PDE and the treatment. She is always indescribably hungry (yes, even for a pug!), a very slow healer (making other illnesses and eye scratches very scary), and prone to infections and cancers (she's had her fair share of both). She has developed calcium deposits on her skin that look like scabby blisters, and her hair doesn't grow back at a normal rate after shedding so there are long periods where she is fairly bald. Initially, Payton would go months (almost a full year once) without incident or seizure. Now, with so much of her brain affected, normal activities (such as peeing and getting excited when company visits) have been triggering seizures on a weekly to semi-weekly basis. Her left side is gimpy having taken the brunt of the seizures. She is blind in her right eye and deaf in her left ear (although her right side isn't much better), and her left legs have

nerve damage that make her a bit clumsy at times. And just recently, Payton has begun to lose muscle mass prematurely.

Hopefully this has helped you all to get a feel for what Payton's battle with PDE has been/is like. The great news is that all of these relapses and related issues probably add up to only a couple of weeks of "bad" days. In fact, you'd be hard-pressed to notice she's at all sick if you met her (well, aside from her thin coat of hair!). Payton has a great quality of life and is happy – despite the disease. Dr. Podell just keeps shaking his head in amazement every time we see him at Payton's regular check-ups.



So if you ever find yourself in a similar situation (and we hope that you do not!), don't give up. With the right treatment, patience, love, and prayer, you could enjoy a much longer, quality life with your baby than you might think.

If you have any questions, please feel free to contact us via email (boostrom1@charter.net). Although we are writing this to shed some light on the disease and share our experiences, please, please make sure to consult your own vet if you have fears that you or some dog you may know is ill.

We can't wait to meet you all at the 2012 Milwaukee Pug Fest!!

Love,

Christy and Tim Boostrom (and Payton, too!)

Hi again everyone,

With an aching heart, I must tell you that we had to say goodbye to Payton. Her little body, weakened by both the disease and the drugs that helped prolong her life, just couldn't take any more.



March 21, 2003 - March 30, 2012

In the end it wasn't the seizures that took Payton's life, but a nasty infection in her lungs, most likely a severe bacterial pneumonia. Years of immunosuppressive drugs made even the smallest bug a battle for Payton. And this time there was so much fluid building up in her lungs that Payton's little body just didn't have the strength to fight to breathe while fighting off the infection. She went peacefully with Tim and me by her side. Payton fought hard her entire life, and without hesitation I declare her victory over PDE. There is no one (furry or not) that I have known in my life to fight with so much courage and determination, with so much love and passion. I have posted two tribute videos/slideshows on YouTube, <http://www.youtube.com/watch?v=q6i6g1sa0XQ> and <http://www.youtube.com/watch?v=JcbWV7jEIE4>.

I plan to keep her blog, Pugnacious P (<http://pugnaciousp.blogspot.com/>), on-line as long as Blogger will host it, so Payton's story will always be just one Google search away to anyone that may need it. Yes, you might see an update or two occasionally if there is more I can share regarding PDE, and I will strive to keep the PDE related links and material up to date. I will also post PDE related information on my FaceBook profile, Payton Boostrom. Hopefully I will be able to write about some real breakthroughs! I am so proud that Payton is a part of Dr. Kim Greer's PDE research; it gives meaning to all of her struggles and early death, so even now Payton can help kick some PDE butt! If your pug or a pug you know has been diagnosed, please consider reaching out to Dr. Greer when the time comes. Monetary donations are always welcomed too. If you have trouble reaching her, please feel free to email me, and I'll help in any way I can.

Our trip to Milwaukee for Pugfest 2012 was very emotional, as you can imagine. I was heartbroken over the fact that Payton could not be a part of the 1000 Pugs project (<http://www.1000pugs.com/>), super modeling for Miss Amanda, and that she was not be there to meet all of the wonderful Pugfest organizers and attendees. I had even purchased a new harness and matching bandanna custom embroidered with her name and "PDE Survivor" for Payton to wear on this trip.



I took this picture the Monday before Payton passed away. She was not happy that I was delaying lunch, so it's not the best, but it's the only one we have of her all decked out in her new harness and bandanna.

But we are glad that we made it. The Pugfest people have been so supportive in our cause to raise awareness of PDE, and we wanted to do it for Payton. I wore Payton's bandana around my neck and had Tim and my dad by my side for support. Maybe you saw us walking around?



I must say that we were so honored that Payton was remembered just before the Blessings of the Pugs and even in the festivities the day before. So many people that we never met reached out to us, and we can't thank everyone enough. It makes us so happy to know that Payton's life touched so many. She certainly knew how to live life and beat all the odds living with PDE for 5 ½ years to the age of 9. For these reasons, the name of this article is still perfect. I hope Payton's story continues to amaze and inspire. If anyone ever has any questions about PDE or if there is anything we can do to help raise awareness or share information, please let me know (boostrom1@charter.net).

Love,

Christy

PDE resource links:

- <http://pugman.com/Pug%20Information/Pug%20Dog%20Encephalitis.htm>

- <http://www.pugs.org/indexhealth.htm> (Pug Dog Club of America has many links on the left side of page)
- <http://www.pugvillage.com/pug-health/pde-just-facts>
- <http://www.pugcentral.com/pde.html>
- <http://www.vgl.ucdavis.edu/services/PDE.php> (website to order test kits for susceptibility)
- <http://www.iue.edu/nsm/research/greer/> (contact information for Dr. Kim Greer, PDE researcher)