

## MURPHY'S DIARY – Part 4

2002

This is the year that Murphy's seizures returned. In truth, we'll never really know why. His neurologist was not very supportive of the notion that acupuncture was helping, but didn't interfere. She did feel he was on too high of a dose of KBr however, and eventually convinced me to lower the amount. Part of me felt this was the wrong thing to do, but I didn't stand my ground. Murphy's seizures returned within two months. Perhaps they would have anyway. But I'll always feel some blame for not being a better advocate for my boy. Guilt for what we might have done differently is always a part of living with an epileptic pet.

**January 11** – Acupuncture with Dr. Pascoe. Over 15 months seizure free. Bile acids test done last November shows no liver changes. Will keep Murphy at 75mg PB BID until we see Dr. Rylander. (KBr still 7cc [4 + 3]).

**February 8** – Acupuncture with Dr. Pascoe. Over 16 months seizure free.

**February 19** – Neuro re-check with Dr. Rylander. Did PB levels and KBr levels. Murphy lost 4lbs!!

**March 1** – Murphy's KBr level 3.4. Dr. Rylander concerned it's too high and could account for his being more ataxic the last few months. Interestingly, he was very high in January of 2001 and then returned to a lower level (without changing his meds) in July of 2001. Summary of Murphy's KBr levels:

March 2000 – 2.4 (on 1400mg)

May 2000 – 2.2

July 2000 – 2.6

(started acupuncture in August 2000 – had last seizure in September 2000)

September 2000 – 2.2

January 2001 – 3.2

July 2001 – 2.6

February 2002 – 3.4 (and much more ataxic)

Goal – to keep Murphy's levels at 2.6, while having acupuncture once a month. There have been no dietary changes. Will lower his KBr to 1200mg, starting March 2, for one month. If ataxia lessens, will raise his dose to 1300mg. Another Bromide level will be done at the end of April. If level still over 3, will lower him to 1200mg. If level dropping below 3, will keep him at 1300mg and repeat Bromide level in 3 months.

We are suspicious about why Murphy's KBr levels wax and wane when his dose remains constant and his diet never changes. The only sign that he may be toxic is more ataxia the last two months. But that has also waxed and waned, on its own, over the past year.

**March 8** – Acupuncture with Dr. Pascoe. Will continue every four weeks while lowering KBr.

**March 17** – Murphy's ataxia greatly improved. This was far too soon after decreasing his KBr. I suspect his level is dropping (independent of the KBr reduction) as part of the fluctuation I suspect occurs seasonally. I've increased his KBr to 1300mg. Will do a Bromide level at end of April.

(March 19 – increased to 1400mg)

**April 12** – Acupuncture with Dr. Pascoe. A little more ataxic afterwards, but was back to "normal" in a couple of days.

**May 14** – Acupuncture (went almost 5 weeks). Feeling good. Not much ataxia. Found out Murphy's KBr level was 2.6 (again). (2.56)

**May 25** – 2:20am: First seizure in 20 months. Yesterday (the 24<sup>th</sup>) was his anniversary. Mild grand mal, lasted approx. 45-50 sec. No pee or poop, just a little saliva. Hardly any post ictal. Took him out to potty, gave him a spoonful of vanilla frozen yogurt with 4-5 drops of Rescue Remedy. Went right back to sleep. Fine in a.m. Found out last week his actual KBr level on last test was 2.56. He's been feeling extra frisky and hardly shows any ataxia. I guess this kind of worries me. I hope this is not the start of more seizures!

**June 1** – 3:30am: Grand mal. 2<sup>nd</sup> seizure. Exactly 7 days apart. Slightly over a minute. More violent. Some vocalization. Peed. Went outside to poop. Two spoonfuls ice cream with 5-6 drops RR. Right back to bed and to sleep. Fine in a.m. Murphy is still not ataxic, which makes me think his KBr level is too low. Will have it checked again.

**June 1** – 7:30pm: Grand mal seizure. Longer, more violent. Closer to 2 minutes. Very little post ictal. RR in ice cream.

Note: Murphy has not been normal for most of day. Anxious and "clingy".

**June 2** – 12:30am: Partial seizure. Circle, eye blinking, head twitch, falling down. Then back on feet and repeat. Responded to his name and would try to follow me. Applied OC (ocular compression) for first time. Stopped and went into normal post ictal behavior. RR did not help as much. Gave him 5mg valium. Slept OK rest of night. Fine next day.

Note:

June 1, 2, 3 & 4 – loaded KBr – 2400mg.

June 1 – raised Pb to 90mg BID.

**June 4** – Acupuncture with Dr. Pascoe. Will return to weekly therapy.

**June 5** – Doing fine. Only slightly ataxic. No seizures so far. KBr level – 2.7. Drinking more water, peeing more. Start 1500mg KBr today.

**June 11** – So far, no more seizures. A little more ataxic, but not bad. Acupuncture with Dr. Pascoe. Felt very good afterwards.

**June 18** – Acupuncture. Feeling very good. Very little ataxia. Will start coming every other week.

**June 19** – 1:00am: Very short GM seizure. 17 days this time. Post ictal about one hour during which he had 4 facial focal seizures about 5 seconds in duration about 60 seconds apart. Could be stopped by applying OC. Gave him 5mg valium and RR on ice cream. Calmed down and slept the night. Very OK the next day.

**June 21** – Continues to feel extra good. Hardly any ataxia. This seems a little strange 21 days after increasing both his Pb and KBr. Plan another KBr level after July 4. Will also do bile acids.

**June 26** – 4:40am: Very short (30 seconds) GM. Hardly any post ictal phase at all. RR in ice cream and back to sleep. Talked to Erin in a.m. Will increase his KBr to 1600mg (4cc BID) and his p.m. only Pb to 105mg. His a.m. will stay at 90mg. This time he only went 7 days between seizures.

**June 27** – 1:40am: Another short GM. This is not good! Short, easy post ictal phase. Gave him a valium this time. He was restless and "not his normal self" all the following day, but did not seize. Settled down by evening. Increased a.m. Pb to 105mg and p.m. Pb to 120mg.

**July 1** – Still no seizures, but finally showing increased ataxia. Not too bad yet. Will see about returning to weekly acupuncture for awhile longer.

**July 3** – Acupuncture with Dr. Pascoe. Will return to weekly sessions until we see where this is all going.

**July 4** - One week seizure free. Ataxic, but still doing OK. Drinks more water. Probably the increase in KBr.

**July 8** – 9:45am: GM seizure while out playing with his ball. Very unusual for him to do this, though he has a couple times before. Lasted about 45 sec. with a couple of minutes lying still but not fully aware. When he finally stood he was able to walk home very slowly. Had his ice cream and RR. A little restless for another ½ hour, then settled down. This time he went 11 days. This seizure occurred right before his a.m. meds. Will increase his p.m. only by another 15mg (135mg). Everything else unchanged while we wait and see.

**July 9** – 11:15pm: GM seizure while sleeping. Lasted around 60 sec. with longer than usual post ictal phase (4 or 5 minutes). Lots of salivation and pee. Ice cream and RR plus 15mg valium and back to sleep. Fine in a.m. (also gave him additional Pb – 15mg). Pb now increased to 120mg in a.m. and 150mg in p.m. KBr unchanged but will load again for 3 days, starting on the 10<sup>th</sup> (2400mg). Talked with Dr. Rylander re: starting him on another AED – probably Gabapentin. She is agreeable but wants levels and a chem. panel (with T-4) done before starting. This will be done on July 19.

**July 11** – Have stopped loading KBr and will return to 1600mg. He is very ataxic today. I suspect his levels are coming up from the increase in KBr a month ago, plus the added Pb. It may finally be catching up with him.

**July 17** – Acupuncture. 8 days since last seizure. Ataxia has not continued to increase. Leveled off at an OK place, so far. Will continue weekly treatments.

**July 24** – Acupuncture. 15 days seizure free. Doing well. Mild ataxia. Lab results showed everything in normal ranges. Bile acids good. Pb level – 27. KBr level – 3.0.

**July 31** – Acupuncture. Much less ataxic today. Feeling very good. 22 days seizure free.

**August 1** – 12:15am: Very short, very mild seizure. The mildest since his seizures resumed. No pee. A little saliva. Stayed asleep. No post ictal phase at all. Felt fine the next day. Full of energy. Increased his a.m. only Pb to 135mg. p.m. still 150mg.

**August 7** – Acupuncture. Feeling good. Was very restless during treatment. Being a “show off”.

**August 13** – 11:15pm: GM seizure. Approx. 60 sec. No pee with very little salivating. Very quiet post ictal with deep breathing. RR and ice cream. Very alert and active afterward. 12 days between seizures.

**August 14** – 10:20am: GM seizure while out playing ball and running around. This is second seizure in 6 weeks that occurred in morning, while he was active. Lasted 90 plus sec. Quiet post ictal phase. Slow walk home for RR and ice cream and 5mg valium. Increased Pb to 150mg a.m and 165mg p.m. Will call Dr. Rylander re: starting Murphy on Neurontin ASAP. Am considering giving Pb 3 times/day (105mg per dose – at 6:30am/2:30pm/10:30pm).

**August 14** – Acupuncture with Dr. Pascoe. Very restless yet ataxic (a little more than he has been. Probably the added valium).

**August 15** – Pb dose – 105mg TID. KBr still 1600mg.

**August 22** – A little more ataxic. Need to have another KBr level done.

**August 25** – Started Neurontin – 100mg TID. It seems a bit sedating, right from the first dose. This is supposed to level off.

**August 26** – Acupuncture with Dr. Pascoe. We're going to try every two weeks now. 12 days without a seizure.

**August 30** – Very sedated from Neurontin. Not too bad in early a.m., but pretty out of it for the rest of the day.

**September 2** – Severely ataxic. Can hardly walk or get down stairs. This may have to do with the change in his diet due to his diarrhea. The KBr may be too high because of lower salt content. Lowered KBr to 1500mg and Pb to 90/90/90 (270 total – where he was before Aug. 1<sup>st</sup>.)

**September 3** – Ataxia very severe. Strangely, his KBr level is 2.48. This is beyond comprehension, as it was done when he was still on 1600mg! I'm still withholding KBr until he's back on his regular diet or until I see less ataxia. Then I'll return to 15-1600mg. I'm keeping his Pb at 90mg TID. Then if there is no improvement, or he gets worse, we have to cut back on the Neurontin.

**September 4** – Way too ataxic. Reduced Neurontin to 100mg BID, and rearranged Pb though still 270mg total. Back on KBr at 1500mg. His schedule is as follows:

6:30am – Neurontin 100mg/Pb 75mg  
2:30pm – Pb 90mg  
6:30pm – Neurontin 100mg  
10:30pm – Pb 105mg

**September 5** – Ataxia decreased almost from the first. It sure seems to be the Neurontin.

**September 8** – Much less ataxia and able to take walks. I think, as we reduce his Pb (slowly), his ataxia will improve. Then we may be able to add a third Neurontin.

**September 11** – Still doing well. 28 days seizure free. This is the longest since his seizures resumed. Will go another week before reducing his Pb, at night, by 15mg. Acupuncture with Dr. Pascoe. Will go every two weeks from now on.

**September 14** – Returned to Neurontin TID. Lowered late night Pb by 15mg. Schedule is as follows:

6:30am – Neurontin 100mg/Pb 75mg  
2:30pm – Neurontin 100mg/Pb 90mg  
10:30pm – Neurontin 100mg/Pb 90mg

KBr 1500mg (divide in two meals – 3.6cc and 4cc)

**September 18** – A little more ataxic from increase in Neurontin, but not too bad so far.

**September 22** – Ataxia about the same. 39 days seizure free. Have decreased midday dose of Pb by 15mg.

6:30am – Neurontin 100mg/Pb 75mg  
2:30pm – Neurontin 100mg/Pb 75mg  
10:30pm – Neurontin 100mg/pb 90mg

Kbr still 1500mg. Will stay at these dosages for at least a month.

**September 23** – 6:00am. 8 second GM seizure. No post ictal phase. 40 days between seizures. Returned 2:30pm Pb dose to 90mg.

**September 25** – 12:30am. GM seizure approx. 30 seconds. Post ictal lasted several minutes. Moved 6:30 am Pb dose to 90mg. Added 100mg to 10:30pm Neurontin for total of 200mg.

**September 30** – 1:15am. Approx. 30 second GM seizure. Short post ictal. Very restless afterward. Gave 5mg valium.

**September 30** – 5:30am. Second GM seizure approx. 15 seconds. Stayed asleep until 6:00am. More RR and 10mg valium. Very restless all morning. Fine by p.m. Raised 2:30pm dose of Neurontin to 200mg. Goal is to raise 6:30am dose in approx. 2 weeks. May need to go as high as 300mg TID eventually.

6:30am – Pb 90mg/Neurontin 100mg

2:30pm – Pb 90mg/Neurontin 200mg

10:30pm – Pb 90mg/Neurontin 200mg

**October 3** – Certainly more ataxic, but not as bad as when first on Neurontin. Seems to level off more quickly.

**October 4** – Acupuncture with Dr. Beebe (Dr. Pascoe on sabbatical for several months). More sedated for 2 days after. Then leveling off a bit.

**October 7** – Still pretty ataxic, but could be worse. 7 days without a seizure.

**October 9** – Increased 6:30am Neurontin to 200mg. Now on 200mg TID. Pb 90mg TID. KBr – 1500mg.

**October 14** – 4:22am. GM seizure approx. 60 seconds duration. 2 partial seizures during post ictal phase, relieved with ocular pressure. RR sundae and 5mg valium and back to sleep. Fine the next day. Murphy was very ataxic for the two days before his seizure. 14 days between seizures.

**December 4** – 4:15am. Very mild GM seizure approx. 45-60 seconds. 5mg valium. Very subdued rest of morning.

**December 23** – 5:20am. Very mild, short GM approx. 20-30 seconds. No post ictal. I decreased Pb on the 21<sup>st</sup> by 15mg.

**December 23** – 9:05am. GM approx. 1 minute. Post ictal approx. 3 minutes. Restless for approx. 1 hour.

**December 25** – GM seizure at 4:30am.

**December 26** – 12:30am. Very violent GM approx. 90 seconds. Good recovery. Increased Pb to 120mg in p.m. (75mg/90mg/120mg)

## 2003

**January 11** – Very ataxic. Decreased Neurontin in a.m. to 100mg (100mg/200mg/200mg).

**January 18** – Decrease Neurontin to 100mg in afternoon (100mg/100mg/200mg).

**January 20** – Decreased Pb to 75mg/75mg/120mg.

**February 8** – 5:10am. 15-20 second GM. Stayed asleep.

**February 22** – 9:45pm. GM approx. 1 minute. Approx. 2-3 minute post ictal (very quiet breathing). RR and 5mg valium. No pee. Very alert.

**March 2** – Possible seizure in early afternoon (between 2-5pm). Found crate soaked with urine. Not post ictal. Very alert. Gave RR and 5mg valium anyway.

**March 9** – 10:35am. GM approx. 3 minutes. Post ictal. very unsteady and agitated. RR and 5mg valium. Additional 30mg Pb.

**March 28** – Diagnoses Hypothyroid. Soloxine .6mg BID. Pb (75/75/120). KBr 1400mg. Neurontin 100mg.

**April 3** – 4:50am. GM approx. 60 seconds. 2 – 3 minute post ictal. Unsteady and agitated. Two focal seizures – used OC (ocular compression). RR and 5mg valium. Additional Pb (15mg)

**April 4** – 3:00am. Very short, mild GM. No post ictal. Extra 60mg Pb. 5mg valium. Will increase Neurontin back to 100mg TID.

**May 8** – 10:00pm. Short GM approx. 60 seconds. Long post ictal approx. 5 minutes. Poor recovery. Very uncoordinated (possibly blind for ½ hour). RR/melatonin/10mg valium.

**Note: way too ataxic lately. Reducing Neurontin to 100mg BID.**

**May 20** – 10:45am. GM less than 60 seconds. Short post ictal. Good recovery.

**June 5** – 11:45pm. GM approx. 60 seconds. Very long post ictal. Slow recovery.

**June 20** – 3:30am. Short GM. Very mild post ictal.

**June 30** – 10:00am. GM approx. 45 seconds. Post ictal approx. 5 minutes. Very quick recovery.

**July 14** – 5:30am. Very short GM approx. 15 seconds. Short post ictal approx. 1 – 2 minutes. Complete recovery. RR/5mg valium/2 tabs melatonin.

**July 15** – Increase Pb to 90/90/135. 1:00am: GM seizure approx. 1 minute. Post ictal 3 – 4 minutes. RR/5mg valium/melatonin.

5:00am: Second GM approx. 1 minute. Short post ictal. Very restless. Another 5mg valium. 2 more tabs melatonin. Another 60mg Pb.

**August 25** – 9:00am. Mild GM under 1 minute. RR/5mg valium. Pretty unsteady but O.K.

**September 19** – 6:00pm. GM approx. 30 seconds. Post ictal 2 – 3 minutes. RR/5mg valium plus regularly scheduled Pb.

**September 20** – 9:00am. GM approx. 60 to 90 seconds. Post ictal approx. 3 – 4 minutes. RR/5mg valium plus regularly scheduled meds. Also 2 tabs melatonin. Good recovery.

8:30pm: GM approx. 90 seconds. Post ictal approx. 3 – 4 minutes. RR/5mg valium plus extra 15mg Pb. Increase Pb to 105/105/135.

**September 21** – 10:00am. GM approx. 90 seconds. Post ictal approx. 4 – 5 minutes. RR/5mg valium/extra 15mg Pb/2 tabs melatonin. Increase Pb to 120/120/150. Increase Neurontin to 100mg TID.

**Note: Longest period between seizures this year.**

**November 3** – 5:45am. GM approx. 60 seconds. Short post ictal. RR/5mg valium. Possible seizure between 12:30pm and 2:00pm.

**November 6** – Decreased Neurontin to 100mg BID due to extreme ataxia.

**November 9** – Cut Pb by 15mg to 105/105/150.

**November 16** – Decided to slowly take him off Neurontin in hopes of regaining some quality of life. Decreased to 50mg TID.

**November 26** – 5:30am. GM seizure approx. 50 seconds. Post ictal approx. 5 minutes. RR/5mg valium.

**Note: reduced Neurontin to 50mg BID on November 23.**

**December 7** – Reduced Neurontin to 50mg per day.

**December 14** – 4:00am. Short, mild GM approx. 30 seconds. Short post ictal. RR/5mg valium. Quick recovery.

**Note: no longer on Neurontin.**

**December 17** – 4:15am. GM approx. 30 seconds. Short post ictal. Quick recovery. RR/5mg valium. Increase Pb in a.m. by 15mg and late p.m. by 15mg. 120/120/165.

**Note: he's been feeling extra lively the last few days.**

**Murphy's Diary – Part 5 will cover his final year, 2004.**