

**MARK N. BODIN**

Cell: (985) 237-8363

mljcomp@charter.net

mbodin@mcglinchey.com

April 22, 2016

**By Hand Delivery**

Dr. William L. Terral  
Children's Medical Center  
71107 Highway 21 Suite 1  
Covington, LA 70433

Dear Dr. Terral:

I am the father of Jeffrey Bodin, one of your patients. I understand that Jeffrey, who is 18 years old, will not allow you to speak to either his mother or me regarding his medical treatment. As I believe Jeffrey is likely not providing you with an accurate description of his current physical and mental condition, and since I know you require such an accurate description to properly treat him, I'm writing to you. I assure you I only do this as a last resort, and only because we do not see Jeffrey's condition improving to any substantial degree – now to the point that his graduating this semester from St. Paul's is in jeopardy (as is his attending LSU this fall). Frankly, we are at a loss as to how to proceed, and since Jeffrey is technically an adult, how to ensure that he does what is in his best interests.

Simply put, Jeffrey basically lies in bed all day, can sleep for well over eight hours at a time, does not go to school, and rarely eats three meals a day (sometimes not even two meals). He advises that he has strong headaches, physical exhaustion (almost paralysis it seems to a layperson), and \_\_\_\_\_. His mother and I believe there is a mental component at play now as well – whether this is actual depression, anxiety or both, we cannot say.

Jeffrey will say these headaches and exhaustion have been present for years and that he has been falling asleep in class at St. Paul's for years. We can say that he never complained about any such things before last summer, that no one from the school ever advised of any falling asleep in class, that prior to this Senior year he was an A and B (mainly As) student in a mix of honors and regular classes, never had any problems waking early to get to school for something like 7:30 a.m., and participated on St. Paul's Cross Country team (which as you may know at St. Paul's is a physically taxing program).

As I mentioned, we began to see these symptoms this past summer (2015), albeit in much less severity than he is currently experiencing. The Fall of 2015 started out reasonably well, but by the end of the school semester his physical issues worsened and he was missing classes and having problems keeping up with his school work. He did, however, make it through the

semester, although with lower than usual grades in some classes. But basically since the Christmas holidays began and through today, his symptoms have been as described above, to the point where he might go to school for a couple of hours a day here and there, and for many weeks has not made any classes at all. He has, of course, missed a number of Senior-related events, which has not helped his mental condition.

Prior to this Spring, Jeffrey was primarily being treated by two physicians at Ochsner – Dr. Diane Africk (a pediatric neurologist) for his headaches, and Dr. Liudmila Lysenko (sleep medicine, neurology and clinical neurophysiology) for what was diagnosed as narcolepsy and possible sleep apnea. Of course, you and Dr. Casey have been his pediatricians since birth.

Dr. Africk tried a few drugs which provided little or no benefit, and finally prescribed Butalbital – \_\_\_\_\_ mg/day, beginning in \_\_\_\_\_. After seeing no improvement, and in fact a worsening, to Jeffrey's headaches, we obtained a referral from another physician for Jeffrey to see Dr. Ann Conn on the northshore, and he began treatment with her on \_\_\_\_\_. We have been pleased with Dr. Conn's treatment and plan, to the extent Jeffrey has allowed treatment. At the conclusion of his second visit [**OR WAS IT THE FIRST????**], Jeffrey allowed Dr. Conn to speak with me for a few minutes. She told me that her first order of business was to gradually wean Jeffrey completely off of the Butalbital, and in fact he last took that drug \_\_\_\_\_. Since then his mother and I believe we have noticed a slight improvement, at least in Jeffrey's eating habits and – when he is out of bed – physical condition. But I probably should emphasize the work "slight." We do not know if Dr. Conn has discussed with Jeffrey the (what we understand to be) high dosage of Adderall he is still taking, or if she even feels that medicine is within her realm of treatment of him. Dr. Conn did, however, during that early visit with me advise that she contemplated two other treatments to address the headaches (i.e., in addition to getting him off the Butalbital) -- \_\_\_\_\_ and Botox injections. Jeffrey did undergo at least two of the nasal injections, but – he tells us – he and Dr. Conn decided that further injections should be made directly into the neck, and Jeffrey told her he would not undergo these neck injections until after school ended. He currently has an appointment scheduled for \_\_\_\_\_, at which time we believe these injections into the neck will start. As for the Botox, we know that Dr. Conn applied to Blue Cross for approval of this medicine and approval was granted, but we do not believe it has yet been carried out (we do not know if Jeffrey has declined Botox thus far or if Dr. Conn believes it best to do Botox at a later date).

Dr. Lysenko, as I believe you are aware, ordered a sleep study which was carried out on February 2, 2015 at Ochsner Baptist. Another copy of the report is attached hereto. The impression was "suggestive" of narcolepsy and "mild yet significant" obstructive sleep apnea. Dr. Lysenko prescribed a CPAP machine for Jeffrey to utilize at night and Adderall of \_\_\_\_\_ mg/day. [**began at 120 or increased gradually to that amount????**] Jeffrey tried the CPAP machine for one night (he will say he tried it for multiple nights, but this is incorrect), complained that it gave him a headache, and refused to use it again. As an aside, in connection with beginning treatment with Dr. Conn and given that Jeffrey did not make what we believed to

Recipient Name  
April 21, 2016  
Page 3

be a valid attempt to use the CPAP machine, Dr. Rick Casey at our request prescribed the use of the machine, one was obtained on the Northshore, and Jeffrey again only used it for one night (and then only for a few hours). He complained that the mask was uncomfortable and refused to use the machine again. As you are aware, Jeffrey is still on the 120 mg/day of Adderall, although some days he does not take the full dosage (on occasion because he simply is not awake long enough during the day to get all the doses in).

Earlier this year, with Jeffrey's condition not improving and actually worsening, I did some research on narcolepsy in an effort to try to find a doctor or facility to perhaps provide a second opinion, different or additional treatment, etc. I discovered the Stanford Sleep Center in California, which I now understand to be one of, if not the, leading research and treatment centers for sleep disorders. My wife Linda was able to speak with someone at Stanford, who was kind enough to agree to review Jeffrey's sleep study report from Ochsner and let us know if Stanford might have something to offer Jeffrey. After reviewing the test report, the feedback was (a) they would not have diagnosed narcolepsy based on this sleep study (something to do, I believe, with the quality of the "next day" naps they had Jeffrey take), (b) in any event, they would not prescribe 120 mg/day of Adderall to treat narcolepsy (more like something in the range of 10-20 mg/day if needed), and (c) sleep apnea could in some cases result in some (or all?) of the symptoms Jeffrey is experiencing. Stanford advised that Jeffrey might benefit from a sleep study carried out at their facility, and even tentatively offered a date around June 8 [**is this right???**], HOWEVER they emphasized the study would be of no use unless Jeffrey was off both the Butalbital and Adderall. At this point, the Stanford study has not been formally scheduled, and we are not sure it would be of any use, given Jeffrey's refusal to use a CPAP machine.

In the interest of completeness, I should also mention the seizures. As you know, approximately nine years ago Jeffrey was diagnosed and treated (at MD Anderson) for melanoma. After his two surgeries, he underwent (at Children's Hospital in New Orleans, under the direction of MD Anderson) three months of intensive infusions of Interferon, followed by home injections of smaller dosages approximately 3X/week. The home injections were to continue for one year, but after a month or so, Jeffrey experienced a seizure at home (to the ER, tests OK, and released to home). He was told to refrain from the Interferon injections for awhile, which was done, and after a couple of months [**is this correct?????**] was advised to renew the injections. However, shortly after doing so Jeffrey began to experience intermittent shaking (not violent, but apparent) and the doctor recommended discontinuing the medicine altogether. No more seizures until February 26, 2016 when Jeffrey was on a school trip in San Antonio (one of the few school events he's been able to attend in the last four months or so). He was taken to an ER, underwent multiple tests which reportedly were all negative, and release after a couple of hours). I flew to San Antonio and met up with him in the late afternoon – he was somewhat tired but actually pepped up and was able to (and wanted to) accompany his schoolmates that night for dinner and sightseeing. The next day, however, he couldn't get out of bed until mid-afternoon. About two weeks ago, Jeffrey had an incident at home which my wife thought might be a seizure – Jeffrey was in the bathroom and \_\_\_\_\_ (I was at work on southshore); Dr.

Recipient Name  
April 21, 2016  
Page 4

Casey came to our home and by then Jeffrey was better and it was decided he likely had not experienced an actual seizure. We have no idea if the February seizure is related to the drugs he was on at the time (Butalbital and Adderall), an effect of the Interferon taken years ago, or something else entirely.

You may be aware of all of the above, but we thought it best to make sure, given that up to now Jeffrey doesn't want us to participate in his visits. Our current concern is getting him off the Adderall, as it doesn't appear to be helping (and in fact may be contributing to his ongoing headaches) and because unless he's off that medication there is no possibility of another sleep study. My wife and I are certainly not physicians, but we continue to wonder if Jeffrey's symptoms of the last year are really related to sleep apnea, and even if they are not we just want to do whatever possible to get him back to his old self. We very much appreciate all that you and Dr. Casey (and Dr. Conn) are doing for Jeffrey, and very much look forward to finding the solution for what is ailing him. Thank you again.

Mark N. Bodin

cc: Dr. Sherri B. Casey (by hand)  
Dr. Ann Conn (by hand)