

2020-08-28 Neurology - Dr. Monica Noya Santana (Phone Appt)

- 1st Patient Appt Notes

2020-08-28

1:46 pm called 1-504-962-6210

- 1m 3s
- Skype
- Got voicemail. Stating that they were on other line. Or that all lines were full/unavailable.
- Assumed that “they” (num listed for neurology)
- Had been in phone appointment with previous patient.
 - As they changed my in-person appointment.
 - w/UMC neurologist Dr Monica Noya Santana.
 - To a phone appointment.
 - Did this yesterday 2020-08-27
 - Number rec call: 1-504-702-2000
 - 9:15 am
 - 1m 6s
 - From UMC scheduling
 - Hurricane Laura caused UMC to “send staff home early”.
 - On, 2020-08-28.
 - Note: the UMC scheduling said, “Phone number I’d receive call from. Might be “personal” device.”
 - Ie check to see if call received from for Dr. Monica Noya Santana. Was her personal instead of Work (main).
 - For contacts archival purposes.

2020-08-28

3:50 pm received call 1-504-702-2000

- 58m 26s
- Skype
- From Dr. Monica Noya Santana.
- Note:
 - Assume this is not her personal device.

- She was at UMC.
- Believe this is the UMC main (out) line that appears.
- Will have follow-up phone appointment.
 - On 2020-09-08 2:00 pm.
- To follow-up on discussed treatment options.
 - She will discuss w/her team.
 - All the records I read out loud to her.
 - MRI's from 2008-08-08
 - Which have no record of within Ochsner's system.
 - Web portal for the MRI's that have some of within it.
 - Which I walked her through on how to get too.
 - Go to MyOchsner -> Go to "Test Results"
 - Go To Fall 2016 Dr. Diane Africk listing for Full Brain Scan MRI w/wo Contrast ->
 - Then you click on "show images" ->
 - Loads up the web portal itself (for viewing on web of results) ->
 - Click on the center top-ish dropdown -> then navigate to all the on file (Ochsner) MRI's/CT scans etc.
 - Note:
 - Told Dr. Monica Noya Santana
 - That these are the only MRI's I have access to. In this online "viewer" formatting.
 - So, she would likely not be allowed access to the others. On file w/MD Anderson Cancer Center.
 - Likely
 - "I don't need to know"
 - ->
 - "Dr doesn't need to know"
- The Interferon "Notes" on my treatment.
- That my father took within the appointment.
- As that is only record of much of specifics on/at said time.
 - 2008-08-18
- Around seizures/seizure treatments (medication)/that took while on my Interferon treatment.
- 2008-08-14:

- Children's Hosp doc notes
 - Interferon
 - Keppra
- 2008-08-18:
 - "Father's Notes" – "Anti Seizure Meds" (mentions):
 - Keppra
 - Topamax
 - Lamictal
 - Tvileptal
 - "INTERFERON alpha-2b Scheving Corp. (Intron A)
 - Hi dose -> 20 mu/m² 5x/wk 4 wks
 - Lo " -> 10 mu/m² 3x/wk 48 wks
- Discussed the previous treatments of:
- Neurontin (neuropathy)
- Botox Injections (cluster migraine headaches)
- Neurological meds that lowered seizure threshold in high school
- Topamax
- Butalbital
 - I stated it was 325 mg of "aspirin" // 5 mg Codine
 - Given to treat pain secondary to the cluster migraine headaches
 - How it genuinely did help.
 - When I had the migraine, this medication was key. To lessening the burden placed on my body (physiologically).
 - By me taking at night/evening post-school day.
 - Falling asleep b/c of it, knocks out.
 - And then are lessened effects of burden on me.
 - However, noted that it did/does lower the efficacy of my Stimulant Therapy
 - How that is a huge issue.
 - Ie even though I was on the lowest dosage of Butalbital.
 - Only took in the least frequent intervals (3 days).
 - To stay off the Barbiturate induced withdrawal.
 - Which the withdrawal from it 2016-03 or 2016-04.
 - Was in fact extremely difficult and inhibited me from going to school. For period no less than 30 days.
 - As, the withdrawal specifically, was extremely taxing on me b/c the Narcolepsy.

- Note: Was more difficult than the Interferon withdrawal period.
- Spoke of some other things relating to neurological profile over the years. Etc.
 - In recent seizure (grand mal) 2020-02 or 2020-03
 - Seizure study admittance to hospital, or lack thereof.
 - In UMC does not have their facility up and running.
 - She said they would be trying to get it up and running.
 - That Children's hospital does have their facility up and running.
 - That she would have to go to Children's in the 1 or 2 times a year. She goes there.
 - To get the orders entered CHNO system.
 - B/c then I could get done there.
 - She wanted to speak to Dr. Olejniczak 1st though.
 - To coordinate on seizure epilepsy testing/this hospital admittance testing.
 - Also, she noted that the VA hospital does in fact have their facility up and running.
 - Which is what Dr. Olejniczak mentioned. Last time I saw him.
 - So, maybe I'll end up getting it through them.
- We spoke about the Adderall 40mg in their system.
 - She noted that it does in fact have "two"? listings for my current prescription.
 - Within UMC's system
 - And, that one of those listings has the 40 mg listed as a note.
 - On the 30 mg listing itself.
 - Note:
 - Had the nurse enter this in person.
 - 2020-08-19 8:15 am
 - ENT
 - Dr. Pelaez appt
 - For hearing testing
 - Noted: Some hearing damage by Audiologist

- Seeing as how I mentioned to him, how my Mother would (2016).
 - Yell in my ear as I was immobilized in a state of sleep paralysis.
 - Which she tried to change but could not
 - As she said it required the original physician to edit completely.
 - Note:
 - Dr. Monica Noya Santana also could not fix this.
 - It seemed as though it was an IT issue.
 - Note to self:
 - Have Dr. Santana try again
 - On 2020-09-08 phone appointment.
 - To change the Adderall fr 30 mg
 - To 40 mg
 - Instead of current “just noted”
 - Within one of the TWO listings within the UMC system.
 - Under their medications and such.
- Discussed: Neuropathy + Seizures
 - As in:
 - Temperature within the last winter fall/winter/spring 2020.
 - With no heat properly.
 - No ability to go downstairs to eat. B/c constant issues with the freezing cold.
 - B/c heat was not properly triggered to come on.
 - See temperature data project all the rooms, and during that timeframe.
 - As in:
 - Temperature surrounding last (2019) late spring/summer/early fall.
 - Wherein air conditioning was set way to cold.
 - Forced by my mother’s delusions.
 - Plus, my ignorance of our home’s:
 - Airflow
 - Temperature issues.
 - Knowledge gained only through temperature data project.
 - Gaining a heater/heater in my room.
 - Circa 2019-12-00

- Helped a lot.
 - Even though it does in fact induce cluster migraine headaches.
 - At sometimes.
 - If it seems to overwork itself.
 - Otherwise it is fine.
 - Also, rooms humidity content likely impacts the heaters strain on itself.
 - THIS is large factor in its function.
- Got to frequently low 60s f.
- Got to frequently mid 55s f
- During this period.
 - Late spring (Late April 2019 // Air Installation)
 - Summer (2019)
 - Early-Fall to Mid-Fall (2019)
- Spoke of all this in relation to my neuropathy.
 - Etc.

See below:

- For reference/writeup.
- On what I sent parents in text message.
 - Mark Neal Bodin
 - Linda Darlene Rea Bodin
- Surrounding my 2nd Phone appointment.
 - Scheduled for 2020-09-08 2:00 pm.

2020-09-08 2:00 pm

Dr. Monica Noya Santana

September 9th, 2020 2:00 pm

- Phone appointment follow-up
- Setting up "things" w/doctor.
- History/Research/Follow-up w/MD Anderson (treatment etc.)
- The doctor wants to convene with her team. On 2020-09-08.
- W/phone appointment.
- Note:
 - Ensure that it is quiet on that day.
 - I do not schedule maintenance for 2020-09-08.
 - Regarding household
- Doctor requires:
 - Time to perform in-depth research.
 - Into my medical history with "her" team.
 - Of (I assume residents/etc.).
- Ensuring no issues occur w/my seizure threshold.
- Ensuring no issues occur w/narcolepsy without cataplexy.

- Ensuring no issues occur w/seizure threshold being "lowered".
- Regarding the Narcolepsy without Cataplexy.
- Ie reducing the efficacy of current Stimulant Therapy.
- A noted concern.
- B/c of previously used Cluster Migraine Headaches treatment.
- Pre-diagnosis of Narcolepsy without Cataplexy.
- Potential treatments for my Cluster Migraine Headaches.
- Discussed (ie new treatments):
- Since the previous specialist last seen in 2016~.
- 5 years, new types of treatments w/injections.
- That treat frequency and incidence of Cluster Migraine Headaches.
- Instead of just treating pain secondary to cause of migraines.
- As was "exhausted" as an option back in 2016~. B/c of my Narcolepsy.
- Spoke to Doctor briefly of new injections.
- Few I recognized as (from FDA) are current trials.
- Doctor will get back to me after "in-depth research". On availability of these.
- I believe likely one would. As my insurance sent me info about it in the mail.
- Ie to ask my doctor about it. B/c its available in our state, or something.

Note (1):

- ASSUME
- Within next month, or so. I'll be required to go to UMC.
- For in-person w/neurology.
- For scans, etc.
- Before treatment can proceed.

Note (2):

- FYI, was told by Dr. Gonzales at last appt.

-- 2020-08-27 8:45 am

- He'd need me to get an MRI. Around next appt w/him.

-- 2020-11-19 8:30 am