

2020-08-28 Notes (1)

- New Patient Appt
  - 1st Appt
  - With:
    - Dr. Monica Noya Santana
  - On:
    - 2020-08-28 1:00 pm
  - Where:
    - 528 Beau Chene Dr
  - Type:
    - Phone
    - Rescheduled fr in person.
    - B/c of Hurricane Laura.
  - Note (1):
    - 1st Phone Appt
    - Ie successfully completed the appt.
- =Phone // Skype Notes=  
==2020-08-27==  
==9:15 am rec call 1-504-702-2000==  
- 1m 6s  
- My Cell Phone  
- Rec while at appointment for Dr. Gonzales.  
- Rescheduling of Appt (1):
  - Scheduler noted, "Hurricane Laura is causing UMC to 'send staff home early.'"
  - For date of 2020-08-28. Basically giving employees half days at the hospital.- Rescheduling of Appt (2):
  - OG in-person appt at/UMC
  - w/Dr Monica Noya Santana
- Rescheduling of Appt (3):
  - Done on,
    - 2020-08-27\_0915
  - By,
    - UMC Scheduling
  - To,
    - Phone appt w/UMC neurologist Dr Monica Noya Santana.
    - For: 2020-08-28 1:00 pm
- Rescheduling of Appt (4):
  - Note (1):
    - UMC scheduling said, "Phone number I'd receive call from. Might be 'personal' device."
    - Ie check call rec fr Dr. Monica Noya Santana.
    - To see if num is personal. Instead of Work (main).
    - For contact archival purposes.

==2020-08-28==  
==1:46 pm called 1-504-962-6210==  
- 1m 3s  
- Skype  
- Got to voicemail / auto-operator.  
- Received msg playback.  
- Stating: "'They' were on other line."

- Or, Stating: "That all lines were full/unavailable."
- Assumed:
  - "they" (num listed for neurology)
  - Were in ongoing phone appt. W/preceding patient.
- Note (1):
  - Above called "1-504-962-6210"
  - Listed underneath "Neurology Clinic"
  - On, Patient Portal's/LCMC's:
    - "Appointment Details" web page
    - ==2020-08-28==
    - ==3:50 pm received call 1-504-702-2000==
  - 58m 26s
  - Skype
  - From Dr. Monica Noya Santana.
- Note (1):
  - Assume this is not her personal device.
  - She was at UMC.
  - Believe this is the UMC main (out) line that appears.
- Note (2):
  - Will have follow-up phone appointment.
  - On 2020-09-08 2:00 pm.
  - To follow-up on discussed treatment options.
- =Phone // Appt Notes=
  - Nxt Appointment (1):
    - Will have follow-up phone appointment.
    - On,
      - 2020-09-08 2:00 pm
    - To,
      - Follow-up on discussed treatment options.
  - Nxt Appointment (2):
    - Appointment will be post-her "research". On my neurological medical history.
    - Research into my neurological disorders interactions.
    - Research incl possible discussions,
      - w/Dr. Olejniczak
      - w/MD Anderson Cancer Center
  - Nxt Appointment (3):
    - She will discuss w/her "team".
    - The research to be done.
    - And, what was covered in 2020-08-28 appt.
  - 1st Appt Covered // Summary (1):
    - All the records I read out loud to her.
    - MRI's from 2008-08-08
    - Which have no record of within Ochsner's system.
    - However, can be linked to them from past MRI brain scan.
    - That contains a link to the MRI's manufac web portal.
    - Which contains multitude of relevant tests (CT/MRI/etc).
  - 1st Appt Covered // Summary (2):
    - Web portal for MRI's:
      - Noted to her that they have relevancy.
    - Web portal for MRI's:

-- Walked her through on how to get too.  
- Walk thru:  
-- Go to MyOschner -> Go to "Test Results" ->  
-- Go To Fall 2016 -> Dr. Diane Africk listing ->  
-- Select "Full Brain Scan MRI w/wo Contrast" -> Scroll to results ->  
-- Select "show images" hyperlink -> Redirected to MRI webviewer ->  
-- On Redirection -> Wait // Allow Load ->  
-- On Partial Load -> Wait // Allow Full Loading ->  
-- On full Load -> Click on the center top-ish "dropdown" -> Drops-down an index  
"viewable" scans ->  
-- On load of "dropdown" (index of viewable scans) ->  
-- Now ->  
--- Navigate freely to all relevant scans.  
--- Ie any of the on file (Ochsner) MRI's/CT scans etc.  
--- Within the webviewer's index.  
- 1st Appt Covered // Summary (3):  
-- Noted,  
--- To Dr. Monica Noya Santana  
--- These are the only MRI's I have access to. In this online "viewer" formatting.  
-- Noted,  
--- 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"  
- 1st Appt Covered // Summary (4):  
- Noted,  
- "Father's Notes"  
-- Context w/Interferon Info  
- Noted,  
- "Father's Notes"  
-- Desc: Interferon notes on my treatment.  
-- Dad took them in person.  
-- At MD Anderson appt w/me.  
- 1st Appt Covered // Summary (5):  
- Noted,  
- "Father's Notes"  
-- Only record of treatment specifics.  
-- Divulged on/around that date.  
-- Divulged on/at said time.  
- See, at the time, in effect:  
-- "Gag" order w/publications.  
- See, difficulty access "gagged" info:  
-- Ie for myself -> my physicians.  
-- Ie myself -> my continuation of care.  
-- Ie unless myself -> in person requested (at time period) fr MD Anderson.  
- 1st Appt Covered // Summary (6):  
- Noted,  
- "Father's Notes" - "Anti Seizure Meds"

- Seizure info + relevancy.
- Referenced in this doc.
- 1st Appt Covered // Summary (7):
- Noted,
- 2008-08-18
- As,
- Approx date seizures systemic of treatment started.
- To be prominently showed.
- Ie effecting continuation of Interferon treatments.
- See,
- Significant incidence/freq of "tonic clonic" seizures.
- Systemic of Interferon infusions + sub-q injections.
- See,
- Dr. Jaime Morales at CHNO.
- Witnessing and diagnosis of the "tonic clonic seizures".
- This expressed to me, directly date of.
- See,
- How I could not keep jaw from chattering/shaking etc.
- Uncontrollable movements etc.
- While laying on the exam "table", setup.
- "Table"/"beds" commonplace w/indiv exam rooms.
- Ie "tables" paper covers, is pulled over, and disposed of post-exam.
- See,
- Seizures effecting continuation of care. Regarding Interferon treatment.
- Pre-major "gran mal" seizure + cessation of treatment.
- 1st Appt Covered // Summary (8):
- Noted,
- "Father's Notes"
- 2008-08-14
- CHNO doc's notes:
- Interferon
- Keppra
- 1st Appt Covered // Summary (9):
- Noted,
- "Father's Notes" - "Anti Seizure Meds"
- 2008-08-18
- Anti-Seizure Meds Ref:
- Keppra
- Topamax
- Lamictal
- Tvileptal
- 1st Appt Covered // Summary (10):
- Noted,
- "Father's Notes" - Meds Ref
- 2008-08-18
- Interferon Meds Ref:
- "INTERFERON alpha-2b Scheving Corp. (Intron A)"
- Hi dose -> 20 mu/m<sup>2</sup> 5x/wk 4 wks
- Lo " -> 10 mu/m<sup>2</sup> 3x/wk 48 wks
- 1st Appt Covered // Summary (11):

- Treatments - Cluster Migraine Headaches
- Noted,
- Previous attempted treatments.
- Regarding diagnosed neurological disorders.
- Treatments:
- Neurontin
- Neuropathy Idiopathic
- Neuropathy Peripheral
- Botox Injections
- Cluster Migraine Headaches
- See,
- Meds w/Migraine treatments.
- Lowering seizure threshold in high school.
- Inducing "gran mal" seizures.
- Topamax
- Cluster Migraine Headaches
- Butalbital
- Cluster Migraine Headaches
- 1st Appt Covered // Summary (12):
- Treatments - Butalbital
- Noted,
- I stated, "it was 325 mg of "aspirin" // 5 mg Codine".
- Noted,
- Butalbital was prescribed to treat pain. Secondary to the cluster migraine headaches.
- Noted,
- Butalbital wasn't to "treat" cause of migraines.
- Ie the brain + cns dmg systemic of Interferon.
- 1st Appt Covered // Summary (13):
- Treatments - Butalbital
- Noted,
- How Butalbital genuinely did help.
- Reduce stress on my body.
- Physiologically, to noticeable effects:
- Lessened strain on body, fr pain.
- Strain was very noticeable pre-Butalbital treatments.
- Strain's absence was very noticeable on-Butalbital treatments.
- 1st Appt Covered // Summary (14):
- Treatments - Butalbital
- Noted,
- Directed to take at night.
- To "attempt" lessening unavoidable effect on Stimulant Therapy.
- Ie w/Stimulant's efficacy in treatment.
- Ie inb4 promoting wakefulness.
- Ie inb4 raising seizure threshold.
- 1st Appt Covered // Summary (15):
- Treatments - Butalbital
- Directions:
- Nightly,
- Nightly b/c = sleeping on Butalbital.

- Lessening tension/physiological exhaustion. By alleviating pain.
- Ie knocked me out (narcolepsy).
- As needed,
- On days, when induced Cluster Migraine Headaches.
- Minimum dosage,
- Min 1 dose per 72 hr interval.
- Note,
- Always maintained this minimum dosing req.
- As dangerous Barbiturate related withdrawal can occur. From not adhering to min.
- Note,
- More dangerous to me, specifically.
- B/c physiological strain from withdrawal.
- As, the withdrawal specifically, was extremely taxing on me b/c the Narcolepsy.
- Lowering seizure threshold.
- Effecting // nullifying Stimulant Therapy treatment.
- During the actualized period of induced Butalbital withdrawal.
- During approx March/April 2016.
- Was extremely difficult ->
- Inhibited me from going to school.
- For period no less than 30 days.
- 1st Appt Covered // Summary (16):
- Treatments - Butalbital
- Noted,
- No-relationship b/w migraine treatment, and, treating the "sleeping" w/Narcolepsy.
- 1st Appt Covered // Summary (17):
- Cluster Migraine Headaches
- Noted,
- Induced by light, sound, vibration.
- 1st Appt Covered // Summary (18):
- Cluster Migraine Headaches
- Noted,
- Light:
- Alleviated by transition prescription lenses for my glasses.
- In non-controllable environment.
- Solved by mitigation of bright environment.
- Ie a controllable environment, light set to accommodating me.
- 1st Appt Covered // Summary (19):
- Cluster Migraine Headaches
- Noted,
- Sound:
- THE largest uncontrollable factor. IN inducing migraines.
- Past abuse by:
- Mother (screaming/yelling)
- Father (likewise same)
- Uncontrollable enviro sounds:
- Vacuuming
- Outside "yard work"/"landscaping"/"road" work.
- Semi-controllable "normal" enviro sounds:
- Associated with any High School Environment.

- 1st Appt Covered // Summary (20):
- Cluster Migraine Headaches
- Noted,
- When I had the migraine, this medication was key.
- To, overall treatment holistically.
- By, lessening strain on body.
- 1st Appt Covered // Summary (21):
- Cluster Migraine Headaches
- Noted,
- Butalbital did/does lower efficacy of Stimulant Therapy.
- Is a huge issue.
- That cannot be allowable regarding dangers of ineffective Narcolepsy treatment.
- Seizures/and or death by fall risk.
- 1st Appt Covered // Summary (22):
- Past Tests / Seizures
- Noted,
- Recent seizure "grand mal":
- 2020-02 or 2020-03
- 1st Appt Covered // Summary (23):
- Future Tests / Seizures
- Noted,
- Seizure study planned admittance to hospital
- Is a 1 wk monitoring hosp admitted period.
- For seizure + epilepsy monitoring, and documenting.
- 1st Appt Covered // Summary (24):
- Future Tests / Seizures
- Noted,
- See,
- Lack thereof, w/acquiring continuation this care.
- Tbd on,
- When? // Where?
- 1st Appt Covered // Summary (25):
- Future Tests / Seizures
- Noted,
- Ie UMC does not have "their" in house facility up and running.
- Is planned, not actualized.
- 1st Appt Covered // Summary (26):
- Future Tests / Seizures
- Noted,
- Doctor said, they would be trying to get it up and running.
- Doctor said, CHNO does have their facility up and running.
- That she is employed/faculty at CHNO too.
- Sparse appointments scheduled at CHNO, few times a yr.
- 1 // 2 per yr.
- Doctor said, she has to be physically at CHNO.
- To get orders in for CHNO seizure monitoring facility.
- 1st Appt Covered // Summary (25):
- Future Tests / Seizures
- Noted,
- Doctor said, wanted to coordinate w/Dr. Olejniczak.

--- Prior to scheduling me at CHNO.  
-- Also, to coordinate my care w/seizures.  
-- Also, doctor noted,  
--- The VA hospital does have their facility up and running.  
--- Mentioned by Dr. Olejniczak too. At last appointment.  
- 1st Appt Covered // Summary (27):  
- Records UMC - Adderall Entry  
- Noted,  
- We spoke about the Adderall 40mg in their system.  
-- She noted that it does in fact have "two"? listings.  
-- For, current script of 40 mg TiD.  
-- Within, UMC's sys.  
-- Note:  
--- One (1 / 2) of the Two (2 / 2) described entries.  
--- Has 40 mg only listed as a note, on the previous 30 mg TiD listing itself.  
- 1st Appt Covered // Summary (28):  
- Records UMC - Adderall Initial Entry  
- Noted,  
-- Entered by nurse  
-- On prev 30 mg entry.  
- 1st Appt Covered // Summary (29):  
- Records UMC - Adderall Initial Entry  
- Noted,  
-- Had // Saw // Witnessed  
--- Nurse enter this in person.  
--- She tried to change, but, could not.  
--- She said, "required the original physician to edit completely."  
-- On,  
--- 2020-08-19 8:15 am  
--- ENT  
--- Dr. Pelaez appt  
--- For hearing testing  
--- For ear compaction 6 month treatment  
- 1st Appt Covered // Summary (30):  
- UMC - ENT  
- Noted,  
-- Some hearing dmg:  
--- Reinforced by one (1 / 2) of the Audiologist's reports.  
-- No dmg:  
--- Verbally Expressed  
--- On date of, by Audiologist to me.  
--- Lessening above report's (1 / 2) confirmation.  
-- No dmg:  
--- Reinforced by the other report's (2 / 2) confirmation.  
--- Of, "no dmg"  
-- See,  
--- How mentioned on query.  
--- To Audiologist + 2 trainee/resident witnesses.  
--- How my Mother would (2016):  
---- Yell in my ear.



---- As, I was immobilized in a state of sleep paralysis.  
---- Unable to defend myself against noise, nor mitigate the induction of Cluster Migraine Headache.

- 1st Appt Covered // Summary (31):
- Records UMC - Adderall Duplicate Entry "Fix"
- Noted,
- Dr. Monica Noya Santana also could not fix this.
- Seems as tho another "issue". IT?
- 1st Appt Covered // Summary (32):
- Records UMC - Adderall Duplicate Entry "Fix"
- Noted,
- Request Dr. Santana attempt again.
- On,
- Scheduled 2020-09-08 2:00 pm.
- Phone appointment.
- To,
- Change erred UMC medication entry.
- Adderall 30 mg TiD -> To 40 mg TiD
- From current "just noted" on another entry.
- To, its own up-to-date entry.
- 1st Appt Covered // Summary (32):
- Neuropathy? + Seizures?
- Noted,
- Temperature within the last winter fall/winter/spring 2020.
- Ie lacking proper heating.
- Increased frequency and incidence of neuropathic symptoms.
- greatly/extremely
- Increased frequency and incidence of seizures induction.
- greatly/extremely
- Relation to neuropathy lowering seizure threshold?
- Due to physiological burden of the constant pain?
- Due to some sort of stimulation? Of nervous sys inducing seizures?
- 1st Appt Covered // Summary (33):
- Neuropathy? + Seizures?
- Noted,
- No ability to go downstairs to eat.
- See,
- Above increased seizure incidence.
- See,
- B/c constant issues with the freezing cold.
- See,
- B/c heat was not properly triggered to come on.
- 1st Appt Covered // Summary (34):
- Neuropathy? + Seizures?
- Noted,
- See,
- Temperature data project.
- Data on household rooms.
- During relevant timeframe.
- See,

--- Wherein air conditioning was set too cold.  
--- Around,  
---- Late Spring  
----- Late April 2019  
----- Initial Air Install // Sys Changes  
---- Summer (2019)  
----- Set too cold (user error)  
---- Early-Fall (2019)  
----- Set too cold (user error)  
---- Mid-Fall (2019)  
----- Set too cold (user error)  
-- See,  
--- Low recorded Temperature.  
--- Got to frequently low 60s f.  
--- Got to frequently mid 55s f  
-- See, causes:  
-- Forced by my mother's delusions.  
-- My own ignorance of our home's:  
--- Airflow  
--- Temperature issues.  
-- See, changes:  
--- Ignorance is solved.  
--- I gained knowledge of temp issues w/household.  
--- Ie, my, ignorance no longer inhibits regulation of temperature.  
- 1st Appt Covered // Summary (34):  
- Neuropathy? + Seizures?  
- Noted,  
- See,  
-- Gaining a heater/heater in my room.  
-- Circa 2019-12-00  
-- Helped a lot.  
--- Now that knowledge on its proper usage is held.  
-- Even tho,  
--- Heater induces Cluster Migraine Headaches.  
- See,  
-- Heater "overworking" itself.  
- See,  
-- Heater + humidity + overworking // strain.  
-- Humidity is likely factor.  
-- In heater's rate of stress build-up // tolerance.  
- 1st Appt Covered // Summary (35):  
- Neuropathy? + Seizures?  
- Noted,  
-- See,  
--- Spoke of all this in relation to my neuropathy.

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2020-08-28 Notes (2)

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.
- Ie 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