

It's Treatable But Rarely Curable: The Long Road To Recovery From Long Vax

Pierre Kory, MPA, MD
President, Chief Medical Officer, FLCCC

Kaleah Miller, Patient

Cindy and Joe Miller, Parents

The Journey Through “The System” Before Arriving At The Leading Edge Clinic

“There’s No Such Thing
As A Coincidence”

Sweet 16

September 18-19, 2021

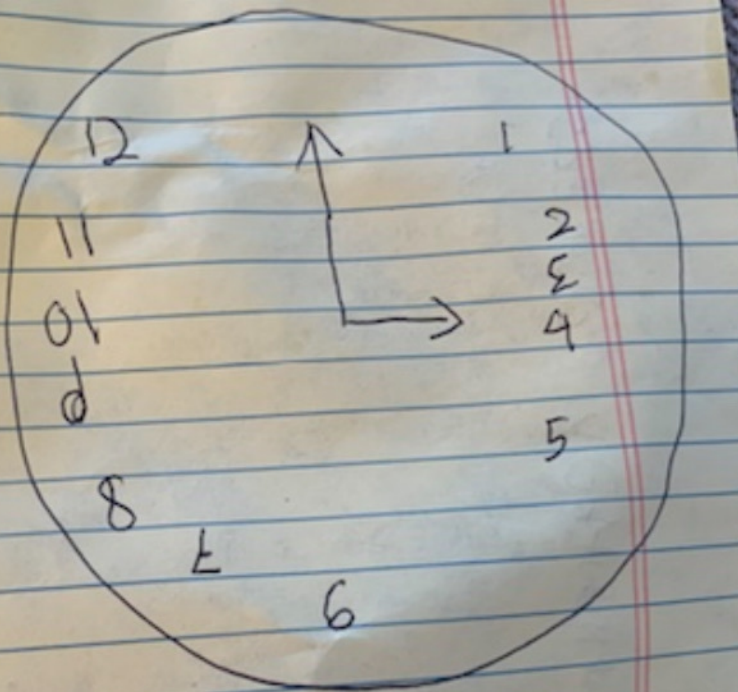


Twisting and contorting



PEANUT BUTTER CRACKERS

Peanut butter crackers



Can she tell time?

Is Kaleah's brain on fire?

Mayo Clinic

- “Not an emergency”
- “Non-life threatening”









LIVE





June 2022, Initial Consultation - History of Present Illness

- **16-year-old fully-functioning female who prior to vaccination liked to perform and sing and do plays. In September of 2021 she was vaccinated in the middle of her period which caused it to stop that day. Within an hour of injection, she complained of a metallic taste in her mouth. She then developed body aches, fever and felt severe malaise for three days. Although the malaise initially resolved, the aches have never stopped to this day. Initially the aches were in her legs, but then moved to pain and aches “in her bones.” Soon after she started to complain of brain fog given that she couldn’t concentrate or do work and although she was doing school online, she was having increasing difficulty.**
- **2 days after the vaccine her mother felt she was developing “cerebral palsy.” She started developing what they called “seizures” - although consciousness was retained, she couldn’t communicate and she was frothing at the mouth, yet she could hear and remember her parents during these episodes. She was mad when people walked away from her during them. This episode of body shaking and squealing would go for 4 hours then stopped for 50 minutes and then would go for another five hours.**
- **After these episodes she was in contorted positions with her limbs contracted and stiff. She could not feed herself because she could not control a spoon or a fork. She was drinking through straws. During these episodes she did not like restraining by her parents. She remembered all of the episodes.**

History of Present Illness Con't

- She continued with limb contractions, stiffness and contortions, could not walk, and her parents had to drag her to the bedroom on a sheet and she was fed by her parents. Her mother noted that at night she had to sleep with her because she noted that her daughter was stopping breathing, and would desaturate to 82%, and the mother had put her on her CPAP machine in order to help her breathe. There were three episodes of this.
- These episodes of thrashing squealing and contortions would last 4 hours and then break for 15 minutes, with the majority occurring after activity. Her father says that she “pays for” activities afterwards, for example, she can ride a horse for 2 hours but then pays for it as the episodes will then not cease for 6 hours. She went to the rodeo for the other day, and although Kaleah says that it was worth it but, she had many severe symptoms after she arrived home.
- She also has many episodes of thrashing and contortions when she then locks into stiffness. She has broken off the foot pedals of her wheelchair multiple times. Other symptoms include fatigue, post exertional malaise, temperature dysregulation, she often feels hot and cold and also develops chills and sweats. Her skin has become very sensitive such that doesn't want to be touched, and in addition her scalp and her hair bother her. All of these symptoms get worse at night.

Episodes Similar To Initial Consultation Exam



IMPRESSION/PLAN:

- Summary: Fatigue, PEM, Brain Fog, dysautonomia, sensory neuropathy, motor neuropathy, skin sensitivity. Severe, repeated dystonic episodes. Occasional episodes of central sleep apnea causing severe hypoxemia requiring non-invasive ventilation. **“System” Diagnosis: Functional Neurological Disorder.**
- Impression: “Long Vax,” i.e. Post-Vaccination Injury Syndrome, consistent with ME/CFS. Numerous mechanisms possible: severe neuro-inflammation, micro-circulatory clotting, mast cell activation, macrophage activation, autoimmune encephalitis, re-activation latent viruses (less likely given tight temporal association with vaccine and unchanging course).
- Plan: Low Dose Naltrexone started 8 weeks ago as per FLCCC protocol, and her father reports that her contortions have become less exaggerated. Today she evidenced good motor skills doing puzzles such that they went out to eat and then did brain retraining. However, at the time of this initial visit Kaleah was in severe distress as she was in the midst of a severe thrashing, contorting, and high-pitched squealing episode while on the couch. The visit was conducted with her parents in an adjacent room, but her shrieking could be heard throughout.

INITIAL THERAPEUTIC REGIMEN

- **Ivermectin** 21mg daily today, take with food
- Increase **low dose naltrexone** to **4.5mg daily** ,
- In two weeks, start **Hydroxychloroquine** 400mg for three days, then 200mg daily,
- I also think we should re-start **Adderall**. Given she has benefited from this in the past
- I also want to stop buspar, and start her on an SSRI called **fluvoxamine**. It is helping many patients with brain fog, has anti-inflammatory properties not found in other anti-depressants..
- **OTC supplements** for micronutrient supplementation and anti-oxidant/anti-inflammatory as follows: **Vitamin B12** - use methyltetrahydrofolate, 5mg a day, **Aspirin** 325mg daily, **Nattokinase**, **High dose nanoparticle Curcumin** -**Vitamin D3** - 5,000 IU Daily, **Vitamin K2**- 100micrograms daily, **Magnesium** - 250mg twice daily, -**Life Extension Brand Bio-Quercetin**, **Melatonin** -**Vitamin C** - as much as you can tolerate. I would take 2,000 mg twice daily, **Nigella Sativa** -**Mitochondrial energy support** : ATP 360Â®, **N-acetyl cysteine (NAC)**: 1000 mg/day , -**Pre-Pro Biotic**
- **Intermittent Fasting** as below

8/6/22 Follow-Up (5 weeks later)

- Mother first described her progress as “doing great”
- However almost all of her **symptom burden persists**
 - She's having **less “big seizures**, but last night she had one and in the early afternoon. During these episodes she sometimes can talk although sometimes she can't. She has them everyday but **they are less severe and less frequent**. She still **can't go out to do prolonged activities** but on a good day she does go out for a walk. She recently did a jet ski for 15 minutes, she frequently does word puzzles (a big change) although **at about the 30-minute mark her symptoms seem to worsen**.
 - She has about **three “good” days a week** as described above, but **only 2 good night's a month** where she actually sleeps well and easily for prolonged time. Her **worst days are when her episodes leave her unable to talk, even unable to see at times, and 1 episode where she stopped breathing** such that she became bradycardic with a heart rate of 37 and a pulse oximeter of 68% however this responded to her mother's application of CPAP. For her symptoms and pain she is now on Klonopin 1 mg twice daily as well as regular Ativan of 1 mg every five to six hours.. She's also tried Tramadol which helped with these severe pain episodes.

PLAN: I will prescribe her more Tramadol, and I discussed with her parents the risks of triple therapy but also the fact that I thought micro-clotting is present and a trial of therapy is reasonable. **Depending on response, I think the next step should be a trial of doubling her Ivermectin to see if she responds more.**

9/22/22 6 Weeks Later

- Since last visit Kaleah went to Gillette children's:
 - EEG found "**nonepileptic seizures.**"
 - Extensive **blood work which was all normal** except for a borderline high protein.
- Update Since Triple Therapy Was Started:
 - Within 2 days they noticed a difference in **improved thought clarity** and noticed she was **able to communicate better** (still having trouble with writing).
 - Now having longer **periods of "having their daughter back"** with less frequency and durations of the distressing episodes.
 - She can even **play a game now** and finish whereas before in the middle of the game she often said she could not do it anymore.
 - She can **last further into the evening up until 9 p.m.** whereas before after 6 p.m. her symptoms tended to flare.
 - She is also **able to walk more.**
 - She is now **expressing a wider range of emotions** than she did prior (now able to show anger, happiness, and even joy at times (all very pleasing to her parents) .
 - Mother does report that she **recently had an episode of a heart rate down to 34 with her oxygen down to 80** and although these episodes are distressing they are happening less.
 - Also her **pain may be overall less** although this is not clear. Mother is now using Voltaren and Aleve and unfortunately despite giving her more tramadol she started to develop hives when she took it.
 - Going to sleep **at night still requires a lot of effort** or her mother must rub her legs and body to get her sleep. Some nights she does not get to bed until 2 a.m. and others such as recently, not until 4:30 a.m.
- **PLAN:** I am very pleased with the response to the triple therapy. It seems that this was clearly a pathologic mechanism that was active. However, although she has made some improvements, she still suffers from a significant number of symptoms. I proposed the following trials of therapy:
 - 1) **Increase the low dose naltrexone** to 4.5 mg daily..
 - 2) **I propose a trial of Ubrelvy.** Once trialed, I request that I be informed of any responses or lack thereof
 - 3) Regarding her triple anti-coagulation, I will consult a colleague to determine the next best steps regarding **continuing vs. transitioning to "natural anticoagulation" vs. trial of cessation**
 - 4) Next trials depending on the above would be **Vascepa (purified EPA fish oil) and/or corticosteroids**

10/20/22 One Month Later

- **Within 1 day of starting Ubrelvy she told her parents that “I am getting better”** and soon afterwards **she said that she felt like herself more.**
- Today she walked 18 steps up the stairs which she has not been able to do since the onset of her illness.
- Pain is more manageable although still present. Further she is able to read a sentence now and even tried to do tongue twisters.

Prior to this she was actually having trouble with feelings of depression and even tears, however this seems to have improved, her parents exposed her to the Carrell Burnett shows and interestingly she is now having a texting relationship with Carol Burnett who is trying to support her emotionally!

- She still has episodes where she **cannot talk however, she can sing songs during these episodes** however she cannot relate her needs or her thoughts. Also in some of these episodes she sometimes **has to develop or adopt a robotic voice.**
- Further although she is able to write, the **writing is backwards both in sentence structure and in word spelling.**
- Of note, since she ran out of Ubrelvy 2 days ago **she is reporting a “diamond” headache** which is a pain that starts on her crown down her nose and goes from ear to ear and this can last hours.

Also disturbingly is that she still has episodes of bradycardia and bradypnea, her mother relates that just yesterday **she had a heart rate of 37 with an apparent oxygen saturation of 23%**, her mother had to slap and shake her and splashed her with cold water as she was catatonic. Further her mother placed her on CPAP and noted that her hands and fingers were cold and this episode eventually resolved.

Another improvement since starting the Ubrelvy is that **she goes to bed easier with less contorting** and further that she is now **doing exercises in the therapy pool** that the family purchased where she says that she likes eliminating gravity. However she is still **limited by postexertional malaise** if she **goes beyond activity of a half an hour** her other symptoms get worse.

In addition, **she still needs benzodiazepines**, for instance for mother gives her Ativan in the morning because **otherwise she is locked up and sometimes foaming at the mouth with dystonia** and cannot exit the bed or start her day. Otherwise throughout the day her mother is reactive and only gives it to her when she is dystonic, and/or distressed in the evening.

IMPRESSION: This is an extremely complicated case of a postvaccine syndrome with I believe numerous pathophysiologic mechanisms at play, with the majority resulting in **numerous areas of neuro-inflammation**. We addressed several mechanisms, and I do believe we need to address more, therefore I proposed the following therapeutic strategies.

- 1) **Double the dose of ivermectin to 36mg for ten days** and report back to me re: any additional improvements
- 2) **At same time, increase LDN to 4.5mg** (one and a half tabs) as tolerated - monitor for insomnia and/or nausea
- 3) **Buy cardiomiracle product from cardiomiracle .com** - drink one serving twice daily
- 4) At next check-in, we should **treat mast cell activation syndrome** as follows:

MCAS THERAPY:

1. Pepcid (famotidine) 40mg three times daily
2. Claritin (or cetirizine if that is what she is on): 20mg twice daily
3. DAO enzymes to block histamine production. For the DAO enzymes, buy the following: NaturDAO 1,000,000 HDU food supplements can reduce food reactions and histamine in various food and drinks (wine) Available on amazon. Take one tablet 5 minutes before meals
- 4) Ketotifen - take 0.5mg at night, increase every 5 nights to 4mg nightly as tolerated. May be limited by drowsiness (which I assume would be a good thing)

2/16/23 Portal Update

- 02/16/2023 4:59 pm - Kaleah's mom, Cindy called asking for a follow up appointment. Will be calling in the next few days to schedule follow up.

Two main concerns for Kaleah has been increase heart rate that remains at 140 bpm and if there is activity or change in temperature it will increase to 170 bpm. Local doctor thought it was serotonin syndrome, but Kaleah's parents disagreed.

Other concern is if someone were to touch the back of Kaleah's skull (occipital lobe region) Kaleah will have severe muscle spasms.

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- 02/24/2023 3:54 pm - **MOM and dad said Kaleah had made about a 70% recovery. States she would not be here if it wasn't for Dr. Kory.**

Kaleah is currently having issues with brain fog and tachycardia. Kaleah states it wakes her up. Mom states her HR average is 120 BPM and when she goes up the stairs or any sort of increase in activity it goes up to 180.

She states she has chest pain with the tachycardia and at other times she has chest pain that lasts for 5-7 minutes that take her breath away.

Follow-Up Visit 3/3/23

03/03/2023 6:25 pm –

- I saw Kaleah in follow up today, unfortunately she was having an episode and could not attend the visit so the visit was held with her mother Cindy.
- **Cindy reports that these episodes seem to occur more often and more severely around her menstrual cycle.** Since last visit she tried an EEG brain feedback therapy and although it did not have a therapeutic effect the clinician said that her **theta waves were apparently "all over the place"**.

I last saw her 3-1/2 months ago, I have reviewed all her medications, and **her current symptoms are increased heart rates, extreme sensitivity to touch and pain in the back of her head which causes muscle spasms, short-term memory loss and persistent bone pain.**

One major positive event is that **she was able to attend homecoming in November but unfortunately she had to leave due to disturbance from the strobe lights.**

Overall her average daily functioning is she **awakens at 7 a.m. but needs to take Ativan in order to be able to move,** she goes to the bathroom ,gets dressed but she is **exhausted at breakfast,** she does have periods of **muscle spasms with feet curling and hand clenching ,periods of not being able to talk which generally lasts less than 45 minutes** however she spends her days doing what she enjoys which is puzzles and word searching **however she is able to go up and down the stairs now her emotional range has improved significantly and her interest and thoughts on science is coming back however reading still "hurts her brain."**

Most importantly is that **when she takes Ubrelvy the days are much better in fact her mother describes them as "miraculous" in that she seems like herself.** She even sings and she complains of no headaches or pains. However there is still trouble with the bone pain. Unfortunately she developed GI side effect with Nurtec and Qlipta

Follow-Up 3/3/23 Continued

She is struggling to eat because of her new pickiness where she only likes velvety foods which generally turn out to be chicken or steak. In addition **her sensitivities to touch have changed which now she can wear jeans**. And she even is now in a relationship with a boy and has gone out to the movies with him. **Overall although she has an extensive medication list in review of this list it seems like every single intervention has had a significant impact including blood thinners.**

Impression/Recommendations:

- 1) **All focus on increasing Ubrelvy supply as this is now a mainstay of her therapeutic regimen.** I fed-exed a supply of free samples today, and will ask Tisha to try to enroll her father into the voucher program to increase supply for the family. If this does not work, I will talk to the pharmacist that supports our practice
- 2) **For her persistent high heart rates, I want to start metoprolol, 12.5 mg twice daily, increase as tolerated** - please update me as to improvements in heart rate
 - a) Please buy and start **zeta aid CRYSTALS product at zetaaid.com**. Please note that your water intake on this product should be reverse osmosis water if you have one, or distilled. Also, avoid generic table salts (have aluminum), and cooking on aluminum pans.
 - b) **Ten days after starting zeta-aid, start this product called cardiomiracle at cardiomiracle.com**. Take as directed. I have lots of positive feedback from this.

Portal Update 5/16/23

- MORE FEEDBACK: 05/16/2023 11:43 am -

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Message for Any Provider from Kaleah Miller (05/15/23 18:42)

SUBJECT: WEEKLY UPDATE

MESSAGE: My definition of weekly is different - mine run together. I'm bad at keeping you updated.

UBRELVY has changed Kallie's world! Alert and cognizant within an hour of waking. (Requires an Ativan to get muscles to work) up until 9-10 p.m. Maintaining a consistent supply is an issue. The pharmacy has had issues getting coupons to work or having them in stock We've had times without Ubrelvy. Has sun-downer-type mental change symptoms

Metoprolol - **World-changing!** Her Apple Watch says only has a-fib 4% of the time. The resting heart rate is 59-65 -vs- 140. Increasing activity level/ energy.

Constant headache is lessened. Since April 1 to date, she's only had 5 episodes of eyes rolled back, flaccid muscles, unresponsive and drooling. Nightly whole body tremors and spasms when she tries to go to sleep. Night-time medications are 100 mg CBD, 440 mg Aleve, 50 mg Benadryl, 5 mg Flexeril, and 1 mg Ativan. Takes 3+ hours on average for her to go to sleep afterward. The WORST time of day.

A NIGHTTIME “EPISODE”



5/1623 Portal Update

- 05/16/2023 4:19 pm -

Thank you for everything you and your family have lost and suffered at great personal expense to CARE and treat patients affected by Long COVID & vaccination injuries. **You've given our bad ass daughter back to us!**

- Despite lingering issues, **she is auditioning for a musical and play on Saturday ! Something we couldn't have envisioned 11 months ago.** She's very gifted and we have no doubt she will be cast. Our prayers were answered when we found you testifying on the reality of vaccine outcomes with Dr. McCullough on the internet.

Portal Update 6/5/23

- 06/05/2023 11:36 am -

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MESSAGE: Kaleah auditioned for and received a part in Addam's Family Musical.

She has attended practice sessions that go from 1 - 5 daily. This is a very rigorous schedule for Kaleah!

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She is doing excellent. She takes her upright walker along for times when her legs become weak. They do allow her to take more than the 7-minute break, per 1.5 hours if she needs.

It is a 30-minute drive to and from the theater. Kaleah is tolerating all of this with only complaints of leg pains when doing the 1.5-hour dance practices.

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NEVER would we have imagined she could even think about doing such a thing! **She is alert, vibrant and talkative until 9:30 at night or later. She then becomes incoherent(unable to communicate) and has spasms before sleep.** She is still able to hear us at all times. (i.e. When we sang the Addams family theme to her, she snapped her fingers at the appropriate time) Sleep & reading are still a problem.

Complaints of bone pain consistently. **DETERMINED & sings constantly. THANKS**

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Follow-Up 6/15/22

• 6/15/22

- **I saw Kaleah in follow up today. She is overall doing better; she joined a play where she has been rehearsing every day with singing and dancing for 4 hours however afterwards she suffers from severe fatigue. Her sleep is still significantly affected in that she goes to bed at 9 or 10 but she doesn't get to sleep until 1 or 3 she wakes up around 7-8 has to take an Ativan because every morning starts with frozen episodes where she can't talk or move, paralysis is total except for sometimes she can move her head or her hands. By 9 a.m. she can wake up sit in bed and she takes all of her medicines and then she can function.**

A new recent symptom is what she is describing is hotspots which is feeling of a burning a hole or pressure in her head, and her parents say that these spots or physically warm to the touch and she still gets hot hands and legs but less frequently.

She also describes a symptom she calls “sonic legs” where she finds that as she tries to walk she suddenly bursts into a run and she finds this uncontrollable, also there are times where she is going up the steps and she suddenly takes 3 steps at a time, and even when she lies down her legs continue doing kicking and walking movements and this can last 30-45 minutes before stopping..

“SONIC LEGS”



Follow-Up 6/15/22 Xcon't

She also **starting to feel random anxiety and episodes of brain fog** she is also hypersensitive to external stimuli, however her chronic and frequent severely dilated pupils have gone away for the past 2 weeks, and her prior visual field deficits are now normal.

- Another interesting manifestation is that there are **times when she becomes mute and can't talk however if her mom puts on the radio she can sing along with songs perfectly.**

In reviewing her prior therapies she states that after the blood thinners it stopped the eye rolling and drooling episodes, and she has not been able to tolerate Zeta-Aid aid because of the amount and taste of the product.

Also in terms of **Ubrelvy on days where she doesn't take it she has more headaches and she starts running backwards her brain fog worsens and she tends to zone out and become mute more often, this has greatly lessened on the days that she takes.** Currently they have sufficient supply for 1 month and they have not tried a higher dose.

I propose the following next strategies:

- 1) Trial of **increased Ubrelvy** - take 100mg for a few days to see if there is added benefit. I will send you my free samples to augment supply. Also see if you can purchase some economically from India if the increased dose helps.
- 2) I want her to **start urolithin** - I prescribed via fullscript, this stimulates mitochondria and will give more energy and endurance.
- 3) **Augmented NAC** - can be purchased from Vitahealth Apothecary in NYC from their website - please start this.
- 4) I think we should start **high dose Vitamin D** as follows: HIGH DOSE VITAMIN D THERAPY (<https://www.coimbraprotocol.com/the-protocol-1>):
- 5) Also start methylene blue and near infrared light therapy as follows:

SINGING WHILE “MUTE”



HIGHER DOSE UBRELVY TRIAL

- 06/22/2023 11:31 am - Provider notified.

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Message for Any Provider from Kaleah Miller (06/22/23 11:23)

SUBJECT: UBRELVY

MESSAGE: Dr. Kory

Kaleah has taken the 100mg daily of Ubrelyv for a week.

She didn't know the dosage was increased. She has requested we NOT tell her when we add or remove drugs so she can be unbiased in her assessments.

She reports that "brain fog" has significantly decreased.

If she reads, works on a puzzle, etc ironically gets a very bad headache that she described as her head being squeezed.

Will now add Renual (urolithin).

Will be mailing you memory stick with videos depicting issues she has suffered.

Cyndi

HIGHER DOSE UBRELVY NOT TOLERATED

- 07/03/2023 3:46 pm -

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Message for Any Provider from Kaleah Miller (07/02/23 17:29)

SUBJECT: Re: Checking in

MESSAGE: UBRELVY 100mg made her have longer periods without brain fog.
It DID NOT reduce head pain.

Went back to 50 mg q day on Saturday (yesterday)

BECAUSE

She explained such tremendous dry throat she had trouble swallowing. Stomachache so bad she didn't want to eat.

Started Renewal Saturday

PORTAL UPDATE

- 07/12/2023 3:29 pm -

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Message for Any Provider from Kaleah Miller (07/06/23 22:19)

SUBJECT: Re: Cindy, Joe and Kaleah

MESSAGE: Dr.Kory: Trisha asked for an update.

Stomach aches & dry throat are improving since we went back to 50 mg of Ubrelvy. She has taken her jet ski out and drove it with dad behind her. Kallie had not been in or on the water since her vaccination.

She has a Seadoo GTX 260. First time out she was hesitating second time out her dad said she had no fear and floored it. She was able to be out 15 minutes each time. Afterwards she curled up on the couch & struggled until she fell asleep. She smiled ear to ear and said " Worth it!"

Thank you for all you do for her

Joe & Cyndi

Portal Update 7/28/23

- 07/28/2023 9:11 am -

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Message for Any Provider from Kaleah Miller (07/28/23 00:00)

SUBJECT: Re: Checking in

MESSAGE: Karen :

Honestly we are all going crazy. Kallie has plateaued in her progress. Anticoagulant therapy has gone well. Evenings are the worst from 10:00 pm . Which is an improvement, used to start at 6 pm. She has taken the jet ski out twice this week. Which she loves, makes her feel human. She use to live in the water. Bittersweet in that it makes her have trouble afterwards. Last time she was able to recognize signs that it was getting to be to much and stopped. Then her spasms weren't as severe

I have not gone to bed with my husband since Sept 2,2021. I stay with Kallie until her body stops having muscle spasms, which on average is 2:00-5:30 am. No regrets, won't do it any different, taking its toll . If she could go to sleep would help us all.

Trying to decide on the stem cell exosome therapy in NY. We need to give her some hope. She is feeling stuck.

Caught me at a bad moment. I apologize. Thank you for reaching out.

Cyndi

Follow-Up Visit 8/2/23

Kaleah's most recent chief complaint is uncontrolled seizures with full jerking and multiple spasms, occurring every night. The patient also experiences significant pain during these episodes, leading to dissociation.

Kaleah has been experiencing **difficulty tolerating higher doses** of medication, with side effects such as severe dry mouth. She has also been **experiencing involuntary leg movements, taking her to unintended places (sonic legs)**. She has been participating in activities such as jet skiing, fishing, and puzzles, but has been increasingly shaky and has trouble sleeping after such activity. A different melatonin supplement with lavender and chamomile has been helping her sleep better, and she has stopped using CBD, which has led to some improvement.

The patient has not tried steroids for uncontrolled contractions but has not tried Cardiomiracle or zeta-aid due to difficulty tolerating powders. She has been taking Benadryl for skin issues and Zyrtec for mast cell activation, but her stomach is sensitive to medications. The patient has been experiencing drowsiness, difficulty sleeping, and head sensitivity. She has also been experiencing abnormal neurological movements and contortions, which can be distressing for her and others. (see prior notes for more comprehensive description of symptom burden).

PLAN

Consider microcurrent therapy for anti-inflammatory effects and energy production. (instructions below)

- next consider a trial of high-dose vitamin D therapy for potential autoimmune benefits.
- Will first get Vitamin D and PTH level as well as semi-quantitative spike ab level –

Brain fog:

- Trial treatment targeting glutamate neurotransmitter with ashwaganda
- Monitor cognitive function and consider further evaluation (trial of memantine) if no improvement.

3 – Mast cell activation Syndrome – try to increase Zyrtec, add Pepcid, and we will start Ketotifen, a mast cell stabilizer

4. Will follow-up with patient who has similar symptom. burden to assess response to stem-cells/exosomes before pursuing.

Portal Update 9/6/23

- 09/06/2023 1:31 pm -

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Message for Tammy Bydlon from Kaleah Miller (09/05/23 19:32)

SUBJECT: Re: Triple anticoagulation follow up

MESSAGE: Tammy

1). No negative side effects to report.

2). **Kaleah continues to improve with longer periods of time, especially in the evenings, where she is not displaying symptoms. USED TO BE by 5:30 pm it was the beginning of our nightly nightmare. Incoherent speech, full body muscle spasms lasting for hours. NOW if she has any of those behaviors they last 15 minutes. She is able to be coherent and verbal until usually 10 pm**

3.) No dental or medical procedures in the near future.

4). **Since adding Ketotofin Kaleah is sleeping by 11:00 pm. Sleeping until 9 am. Still some muscle spasms, MILD in comparison to everything we've seen prior to Ketotofin. Sleep pattern is miraculous!!! Microcurrent therapy is going on 9 days now. Kaleah is using flash cards to strengthen her confidence in math basics - her brain is returning!!**

Thank you so much for all you do. I have not figured out how to get labs for you yet.

Cyndi

Portal Update 1/2/24

- 01/02/2024 12:13 pm -

Update since last visit

Kaleah continues to improve.

Hormones immediately prior to menstrual cycle and during continue to wreak havoc. More “episodes” and difficulties controlling her body movements.

She is looking forward with much anticipation to meeting Dr. Kory in February at the FLCCC conference in Mesa.

She is going in this after for a routine physical and hopefully get the labs Dr. Kory ordered.

Thank you

Cyndi Miller

To: Pierre Kory Respond by: No Reply Necessary

A.A.12/28/23 - 02:08 pm

Update

ANOTHER “EPISODE”



Portal Update

- 01/09/2024 11:11 am -

Dr. Kory had recommended we double the dose of Hydroxychloroquine.

We tried it - it increased the night-time tremors and Kaleah's ability to sleep returned to pre-ketotofin levels.

Yesterday, I stopped it. She did not fall asleep until 5:45 a.m. and she had gone to bed at 9 p.m.

Last night she was able to go to sleep by 10:45 p.m. and woke at 3:30 a.m. for about an hour.

I gave her 2 Ultram and 2 Benedryl, reapplied the Voltaren cream massaged her muscle cramps were rubbed out she was able

to fall asleep around 4:15 a.m

I don't know, I think I've mentioned this before. ALL of her symptoms and muscle spasms, etc. are ALWAYS on her RIGHT side of her body and face.

Her tremors are so forceful that she has to go to the chiropractor at least 4 times a month - she has axial-atlantal subluxations.

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I have had axial-atlantal subluxations and so has 1 of her sisters. So this appears to be a familial characteristic. Hers however occur just from her tremors rather than a traumatic incident.

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Portal Update

- 01/09/2024 3:33 pm -

Note: April

Discontinuation of the Hydroxychloroquine made the increased tremors and difficulty falling asleep stop.

However, last night her heart rate dropped to 34 & her oxygen saturation dropped to 50.

We put my C-pap machine on her, shook and slapped her and rubbed her chest and her vitals returned to normal.

She said before everything happened she had a really strange feeling, got cold and she couldn't breathe, felt like her lungs and heart were spasming. She had a second episode.

Both my husband and I slept with her until 3:30 am

Today she is functioning well. Says she feels like she has an elephant on her chest. No symptoms and vitals are fine. It's always something. We're good. Just wanted you to know discontinuing

hydroxychloroquine stopped

The hours of seizure/tremors.

So thankful for every day Dr. Kory has given us with her.

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Summary Of Treatments And Responses

- 1) **Low-Dose Naltrexone:** contortions less exaggerated, some improvements in motor skills
- 2) **Ivermectin/HCQ/Fluvoxamine:** less frequent and less severe episodes, increased duration of activities, improved ability to do word puzzles, now has 3 “good days a week”
- 3) **Tramadol:** helped with severe bone pain episodes
- 4) **Klonopin:** helps to get her “unstuck” in the morning, able to start her day, helps with flares at night, otherwise gets dystonic, foams at mouth, cannot get out of bed
- 5) **Triple Therapy:** improved thought clarity, improved ability to communicate, “feel like we have our daughter back,” less frequent, less severe “neurologic episodes,” she now lasts further into the evening before symptoms flare, she is walking more, “expressing wider range of emotions” (started to show anger, happiness, and even joy). *Still has very difficult nights, sometimes not calm or soothed until 2am or 4 a.m. “No longer has “stroke” symptoms where her eyes would roll up, she would drool out the side of her mouth and once she returned to a cognitive state, she would experience inability to direct her tongue, paralysis of portions of her body on the right side.
- 6) **Ubrelvy:** within one day, stated “I am getting better,” “I feel like myself more,” walked up stairs for first time, pains more manageable. Able to sing songs at times. “Goes to bed earlier with less contorting, able to do gravity pool exercises. **When she ran out of Ubrelvy, “diamond headache returned.” Later: “the days she takes Ubrelvy are miraculous.” “She even sings and complains of no headaches or pains.”
- 7) **Metoprolol:** heart rates greatly improved, heart pains that awaken her are now minimal, increased energy level
- 8) **Zeta-Aid** – “makes her alert times longer”
- 9) **Ketotifen** – “ince adding Ketotofin Kaleah is sleeping by 11:00 pm. Sleeping until 9 am. Still some muscle spasms, MILD in comparison to everything we've seen prior to Ketotofin. Sleep pattern is miraculous!!!

TRYING TO SMILE – CHRISTMAS 2021



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