Name: Laura Chicos | DOB: 12/4/2007 | MRN: 1763047 | PCP: Carla Adriana Lucacel, MD

H&P - Clinical Notes

Cassandra Kazl, MD at 2/23/2021 10:00 AM

COMPREHENSIVE EPILEPSY CENTER - INITIAL VISIT
Name: Laura Chicos
MRN: 1763047
DOB: 12/4/2007
Date: 2/23/2021

Referring Physician: Self-referred

CC:
Chief Complaint
Patient presents with
- Seizures

HPI: This is a 13 y.o. left handed girl with history of anemia, epilepsy, and MTHFR mutation of unclear significance who presents for initial visit with her mother for additional opinion regarding epilepsy diagnosis and management. The mother provided medical records from birth until now (13 years) to be reviewed (scanned under media).

Although you may be familiar with Laura Chicos's history, please allow me to briefly summarize for the purpose of our records.
Mom had PPD test during pregnancy first negative, then second positive (thought due to BCG). Normal XR chest 1 month after delivery.
Laura received Hep B vaccine after birth, unknown to mom. Mom breastfed and formula (Enfamil) since beginning.
Vaccinated at 2 months, then next day developed rash with severe eczema on arms and face, bleeding like wound. Stopped milk and eggs as they are common allergens, and those changes helped her symptoms. Continued on normal vaccine schedule. Had allergy flairs on and off.
Continued to have 4 and 6 month vaccines.
At 6 months introduced food, allergies waxing and waning.
Per mom, she is allergic to almost everything. Food, environmental, dust allergies.

Around 9 months (Oct 1, 2008) they observed jerks. Always the right side of the body at first, and could have left eye deviated inward. Thought normal baby movements. But happened again, taken to NYU and did EEG which showed spikes, recommended neuro follow-up. On her bday in Dec, they presented to Cornell and saw Dr. Engel where EEG and MRI were done and she was diagnosed with benign myoclonic epilepsy of infancy. EEG on 11/24/2008 showed "midtemporal spikes", then a follow-

up VEEG on 12/2-4 showed "frequent generalized spike and wave discharges, cluster of myoclonic jerks with EEG correlate". She was started on Keppra and vit B6. Would happen shortly after fell asleep, and they soon noticed pattern after eating rather than sleep.
MRI showed pineal cyst and told to follow up. In 2017 cyst no longer seen.

Feb 2009, she went to NYU and saw Dr. Miles. Was in the hospital 3 days and they reviewed everything, still not concerned, given diagnosis of generalized epilepsy. Increased LEV and B6, therapeutic but no improvement in jerking.

Then went to Montefiore and saw Dr. Shinnar, who thought might be myoclonic infantile spasms. Tried ACTH for 2 weeks, which stopped the jerks. Then switched to oral prednisone and the jerks came back. She gained weight, etc. He then started VPA to therapeutic dose which increased the frequency of the events, could jerk from 5-45 minutes. He offered Topamax, but they declined as this would not treat the cause.

Then went to Cohen's and saw Dr. Maytal later in 2009. Developing well, normal, doing what she was suppsoed to. EEG done at that time was normal (at this point some had been normal and some abnormal). He also said he could offer Topamax, which mom did not want to try since VPA was the top choice.

They then tried alternative treatments. Glutamine and Tuarine, craniosacral therapy, homeopathy, allergy elimination technique. Jerks stopped Sept 2009 to May 2010. In May she had a piece of cake from the market and the next morning the jerks came back. Jerks always looked the same.

In 2011, tried bentonide clay in apple cider vinegar to "move toxins in the body", after which she had a reaction of stiffening, which was believed to be an allergic reaction to the bentonide or apple cider vinegar.

Then, in 2011-12 she would have the same jerks, now with dizziness, and followed by whole body stiffening. Stiff, turn head to the right, eye roll, then whole body shaking. Lasted no more than 1 minute. This is what it has been since then until now.

Also saw Dr. Heerey (?) naturopath for gluthionine therapy, Dr. Salerno for heavy metal testing, aluminum was slightly elevated.

2017 they went to Mt. Sinai and saw Dr. Wolf, she repeated MRI 4/16/2017 which was normal. EEG for 3 days on 4/28/2017 showed "Frequent left sided spikes and polyspikes, with temporal predominance". No observable clinical events or seizures. Impression was of localization related epilepsy, he offered Topamax or ?zonisamide again and again they declined as this would not treat the underlying problem.

Evaluated in metabolism clinic at Mt. Sinai, extensive labwork done (scanned under Media) and impression was that she was healthy with no evidence of inherited error of metabolism, signed off.

Larry Palesky, a NY pediatrician who advocates that vaccines are unsafe, nanoparticles that can stain the brain and trigger the immune system. Mom is worried that this is what is causing Laura's seizures. This may happen months to years after a

vaccine. Nanoparticles in the phospholipid membranes can't be eliminated.

2019 went to an allergist who was investigating mast cell activation syndrome as a cause, histamine was elevated in blood, but unable to treat her. Have tried to eliminate histamine from her diet, "almost ketogenic", more plants, less meat. Meat and eggs seem to trigger her seizures.

Currently, has dizziness, nodding head, and gets sweaty, flushed, urgency to go to the bathroom. Happens daily, in the mornings, then 2 hours later. Can also be triggered by urge to urinate. Seizure as above is about 1x/month, unless she eats meat or eggs which can trigger events sooner.

23 and me results showed a MTHFR mutation. No formal testing through geneticist.

Open to ketogenic diet. Tried CBD OTC few months, didn't make any change.

Sleep: Feels tired every morning, no problems falling asleep or staying asleep. Mom sleeps in bed with her and no concern for event overnight. At 12 years old she had an event overnight.
Memory: Very good, no concerns.
Mood: Denies anxiety, depression. Sometimes angry.
School: IS 125 in 7th grade, does great. Is remote 100%.

· Handedness: left handed, has a left handed cousin.
· Pregnancy, labor, delivery, neonatal course: Born full term 39 weeks c-section for repeat. No complications with pregnancy or delivery.
· Development: Normal, met all milestones on time.
· Epilepsy risk factors:
    · CNS infections: No
    · Developmental delay: Normal
    · Family history of seizures: No
    · Significant head trauma: No
    · Febrile seizures: No, but would have more events when sick
· Age of first recognized unprovoked seizure: 9 months
· Age of first daily AED initiation: 9 months
· Number of unprovoked seizures prior to daily AED initiation: Numerous
· Total number of unprovoked seizures: Innumerable, daily
· Status epilepticus/Seizure clustering: No
· Date of most recent unprovoked seizure: Yesterday, 2/22/2021
· Longest seizure free period: 9 months on alternative supplements
· Anti-seizure medications during this period: None
· Definite unprovoked seizure types: myoclonic jerks, ?focal non-motor seizures
· Epilepsy classification: Focal vs focal and generalized features
· Epilepsy etiology: Idiopathic

Subtle Seizure risks: The patient and family were asked and denied any of the following symptoms: nocturnal tonic-clonic seizures or evidence of tongue biting, blood on pillow or unexplained muscle soreness, back pain or headache on awakening;

staring spells, paroxysmal sensory, motor, or autonomic symptoms suggestive of simple partial seizures, or automatic motor behavior (eg, chewing, lip smacking or hand automatisms).

Prior Electrophysiologic or Radiologic Studies:
Routine EEG: See separate scanned results
Video EEG: See separate scanned results
Brain MRI: See separate scanned results
Genetic Studies: no formal testing

Birth History:
Birth History

Born full term 39 weeks, elective c-section for repeat, APGARs 9 and 10, BW 9lb7oz. No complications with pregnancy or delivery.

Developmental History:
milestones have been achieved in a normal sequence and time

Past Medical History:
Past Medical History:

Diagnosis	Date
• Anemia	6/1/2009
• Seizures	10/1/2008

Past Surgical History:
History reviewed. No pertinent surgical history.

Family History:
Family History

Problem	Relation	Age of Onset
• Diabetes *DM I*	Maternal Grandfather	
• Diabetes *DM II*	Paternal Grandmother	

No family history of epilepsy.
No family history of developmental delay/ASD.
No family history of other neurological conditions.

Social History:
Social History

Tobacco Use
- Smoking status: Not on file

Substance Use Topics
- Alcohol use: Not on file
- Drug use: Not on file

Social History

Social History Narrative
- Not on file

Allergies:
Meat, eggs, milk, tree nuts, yeast protein, artificial additives, vaccine components, dust and pollen, "allergic to basically everything" per mom

Medications:
None

Previously Tried Antiepileptic Medications:
Keppra - ineffective
Depakote - ineffective
ACTH - helped then seizures returned when treatment stopped
Oral steroids - ineffective
*No side effects of any, self discontinued

Review of Systems:
CONSTITUTIONAL: parents deny fatigue, weight loss, weight gain
EYES: parents/patient deny vision concerns
ENT: parents/patient deny hearing concerns
CARDIOVASCULAR: parents/patient deny cardiac concerns/chest pain, palpitations
RESPIRATORY: parents/patient deny: cough, shortness of breath/respiratory concerns
ENDOCRINE: parents/patient deny: temperature intolerance, unexpected weight changes
HEME-LYMPH: parents/patient deny: bleeding, bruising
GI: parents/patient deny abdominal pain, nausea, vomiting, diarrhea, constipation
GU: parents/patient deny urinary incontinence. Toliet trained (+/-)
NEURO: As above; also denies headaches, dizziness, weakness, or numbness. Developing on target; denies regression.
BEHAVIORAL: parents/patient deny behavioral or ADHD concerns.
MUSCULOSKELETAL: parents/patient deny: joint pain, joint stiffness, muscle pain, muscle weakness
SKIN: parents/patient deny: rash
PSYCH: parents/patient deny concern for anxiety, depression, hallucinations, irritability

Physical Exam:
There were no vitals taken for this visit.
Wt Readings from Last 3 Encounters:
No data found for Wt

There is no height or weight on file to calculate BMI.
There is no height or weight on file to calculate BSA.

General Examination:
General Appearance: No acute distress, tall and thin/gaunt.
HEENT: Normocephalic, atraumatic, conjunctivae pink, sclerae clear, tongue and

mucous membranes moist.
Neck: Supple with normal range of movement and no meningismus.
Musculoskeletal: Normal muscle bulk.

Neurological Examination:
Mental Status
State: Patient is awake and alert. Patient answers questions and follows commands appropriately.
Language: Speech is fluent. There is no dysarthria. Naming, repetition and comprehension are intact.
Mood and Affect: Normal

Cranial Nerves
CN III, IV, VI: Normal. Extraocular muscles are intact without nystagmus or diplopia.
CN VII: Normal. Facial musculature is symmetric.
CN XII: Normal. The tongue is midline with no evidence of atrophy.

Motor
Bulk and tone are normal throughout. There are no abnormal movements.
All extremities anti-gravity.

Reflexes
Not tested

Sensation
Not tested

Coordination
No dysmetria or tremor.

Station/Gait
Gait: Normal station and gait.

Impression:
Laura Chicos is a 13 y.o. left handed girl with history of anemia, epilepsy of unclear classification, and MTHFR mutation of unclear significance who presents for initial visit with her mother for additional opinion regarding epilepsy diagnosis and management.

Mother is extremely concerned about vaccine components as well as numerous food allergies contributing to formation of Laura's epilepsy, and specifically aluminum and nanoparticle deposition in the brain tissue. We discussed that most if not all people who go on to develop epilepsy after vaccinations were proven to have some underlying genetic cause of their epilepsy. They expressed extreme hesitancy to treat Laura's seizures due to the fact that it would not be treating the underlying cause of her epilepsy, which remains unknown.

We recommended beginning with a prolonged video EEG study to attempt to characterize and classify her epilepsy to guide treatment. We also discussed sending formal updated genetic testing through an epilepsy gene panel, which they were

amenable to. Laura will need treatment for ongoing seizures, and that can be determined pending the EEG study results. While the mother is resistant to medications, she may be open to the ketogenic diet.

The patient should avoid sleep deprivation, and OTC sedating antihistamines such as diphenhydramine as these may lower seizure threshold. General seizure safety precautions include avoidance of baths/swimming alone due to risk of drowning, wearing a helmet on toys with wheels, exposure to open flames and heavy machinery operation due to risk of burns or injury, and heights due to risk of injury should a seizure occur triggering a fall.

Approximately 60 minutes on 2/24 from 09:30 to 10:30 was spent reviewing physical records that were brought in by the family today. These records are scanned into the chart under "Media".

Plan:
- Gene Dx Epilepsy gene panel
- Admission for 72-hour video EEG to characterize background and screen for seizures
- No treatment medications at this time, pending EEG results
- MyChart for fluid communication
- Follow-up: We will see Laura Chicos again in 2-4 weeks after admission and have instructed the family to contact our office if she develops new symptoms.

If you have any questions or concerns, please do not hesitate to contact our office. Thank you for referring this patient to our clinic.

Cassandra Kazl, MD
Pediatric Neurology and Epilepsy

Answers for HPI/ROS submitted by the patient on 2/22/2021
appetite change: Yes
fatigue: Yes
fever: No
unexpected weight change: Yes
nasal congestion: No
dental problems: Yes
ear pain: No
hearing loss: No
sore throat: No
sinus pressure: No
tinnitus: No
nosebleed: Yes
rhinorrhea: No
postnasal drip: No
facial pain: No
chest pain: No
leg swelling: No
palpitations: No
claudication: No
shortness of breath: No

cough: No
wheezing: No
sputum production: No
hemoptysis: No
heartburn: No
constipation: No
diarrhea: No
abdominal pain: Yes
trouble swallowing: No
nausea: No
vomiting: No
blood in stool: No
bowel incontinence: No
dysuria: No
frequent: No
urgency: Yes
urinary incontinence: No
arthralgias: No
myalgias: Yes
joint swelling: No
back pain: No
rash: Yes
itching: Yes
headaches: Yes
double vision: Yes
weakness: Yes
gait problem: Yes
loss of balance: Yes
dizziness: Yes
tremors: Yes
loss of consciousness: Yes
visual change: Yes
sleep disturbance: No
dysphoric mood: No
anxiety: Yes
mood changes: Yes
heat intolerance: Yes
cold intolerance: Yes
menstrual problem: No
polyuria: No
polydipsia: No
hunger: Yes
bruises/bleeds easily: No
adenopathy: No
environmental allergies: Yes

Patient Instructions - Clinical Notes

Cassandra Kazl, MD at 2/23/2021 10:00 AM

Plan:

- Gene Dx Epilepsy gene panel
- Admission for 72-hour video EEG to characterize background and screen for seizures
- No treatment medications at this time, pending EEG results

- Follow-up 2-4 weeks after admission

Seizure Precautions

It is very important to protect your child from injury during a seizure. Here are some tips to help you:

1) Remain calm and do not restrain your child. Stay with your child until the seizure stops.
2) Use a watch/clock to time the seizure. It may be difficult to remember to do this in the moment, but is important to know how long the seizure lasts.
3) If your child is sitting or standing, gently ease them to the floor.
4) If possible, place your child on their side with something soft under their head. Turn their head to the side with face downwards so that secretions can drain out of the mouth and to prevent choking (see picture).
5) Loosen tight clothing, remove glasses if your child wears them.
6) Move hard or sharp objects (tables, chairs, etc.) away so that the child cannot get hurt.
7) If a seizure lasts more than 3 minutes without any sign of slowing down, Diastat may be administered. If the seizure persists longer than 5 minutes, call 911 for transportation to the local emergency department.

What Not to Do

Do not leave your child unattended until the seizure stops.
Do not restrain your child's movements.
Do not try to open your child's mouth or place anything in the mouth (including your fingers), this could cause injury or choking.

After the Seizure

Let your child rest after they are cleaned up (they may have soiled pants or vomited). They may be very tired and sleep for several hours. They may complain of mild headache. Within 15-30 minutes, you should get some response from your child (opening eyes, pushing you away, arousing). If you get no response or are uncomfortable with your child's state, seek emergency help.

Seizure Restrictions

There are few restrictions for patients with seizures. Some activities, however, need special accommodations or must be avoided. We recommended that involvement in contact sports be avoided until seizures are under good control. In addition, your child should never be in water (a pool, bathtub or other body of water) unless directly supervised by an adult who can provide one-on-one supervision and has knowledge of the history of seizures. When participating in activities with wheels or high speed like biking and skiing, a helmet should always

be worn. The ability to obtain a drivers permit or license is determined by the department of motor vehicles and laws vary by state. NY requires patients to be seizure free for 12 months before obtaining a permit.

Additional information about seizures and treatments can be found online at:
https://www.epilepsy.com/
https://livingwellwithepilepsy.com/
http://www.efmny.org/
http://faces.med.nyu.edu/

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