This journal is mostly a reflection of my thoughts and suggestions on my daughter's Maddie 32 days stay at Children's Hospital. Some parts of this journal may be taken by some in a negative light but I am not trying to be mean or unfair. These words are seen through my eyes & our family's experience of the past month and how each of you played a part in Maddie's care. And hopefully how we all could make the Children's Hospital a better experience for kids with health issues in particular seizures. How you choose to take this journal is up to you but I hope each of you will try a little harder to not forget the children that are in your care, and how their families rely on your expertise in getting a healthier child.

Many of the Staff at CHILDREN'S HOSPITAL in particular PICU Dr. C., Dr. T., Lisa, Dr. Z, Dr. R, Dr. T, PICU Nurses Karen, Dana, Respiratory Therapists: Jayme, Denise, Yolitta, Keith, Lesli and Deb, Floor Nurses: Linda, Elizabeth, Shiela and Allison along with Drs. S and Dr. D and many countless others that worked hard on saving Maddie's life and getting her back to her happy self. We are so thankful and grateful for all of those mentions above for the quality and compassionate care that you gave Maddie and our family during this difficult time. However, there are issues that were of a concern that must be addressed so that Maddie and other children will get the best and highest quality care possible those particular issues are found in the document: *Confidential Patient/Family Concerns Report 9/30/12* . As parents, my husband, Chris and I are better educated about some of the seizure medicines that she is able to have and which ones could potentially harm her. We will do a better job of record keeping, learning more about epilepsy, the ketogenic diet, push for more genetic testing, and advocating so that we can help our daughter in the future.

Background information:

My husband and I brought our 7 year old daughter, Maddie to the Emergency department on Friday, August 31, 2012 around 4 pm. The intake nurse saw immediately to Maddie's concerns and she was taken back to a room in the ED without even waiting. Maddie has had seizures since she was only 12 hours old. She has been tested for Retts Syndrome, Angelman, and Prader-Willi syndromes along with a chromosomal microarray which all came back as negative. She was given a diagnosis of cerebral palsy of unknown etiology around the age of one & a half. This diagnosis was to get therapeutic services or equipment with insurance companies. For the first year of her life she was on Phenobarbital and was very lethargic until her neurologist at the time Dr. changed her to Keppra and she began to have more energy and was able to hold her head up the second year of her life. She was even off all seizure meds from age 3 to 4 1/2. Her seizures were pretty much controlled for the first 4 1/2 years of her life. When she turned 5 and started Kindergarten, she began having more breakthrough seizures and we needed to try additional anti-seizure meds in addition to Keppra. Keppra & Topomax were the only 2 meds that seemed to somewhat control her seizures but she would still have 2-3 seizures (5-60 seconds complex partial seizures) spread out in a 24 hour period about 3 out of 7 days. Then seizure activities increased over the last 6 months to 3-5 about 3-5 days a week. In August, seizures became more frequent & closer intervals about 5 days a week. Her primary neurology at the time (Dr. N.) increased her Topomax from 2 1/2 tablets BID to 3 tablets Bid. She became very sleepy and lethargic so he saw her in the office on Thursday, August 23rd because of another patient's cancellation. He ordered Topomax back down to 2 ½ tablets BID, also will try Onfi when Insurance approved so only 1/2 tablet once a day of Onfi starting on August 21st. No seizures and actually saw Onfi working when seizures began to occur. Then that weekend Maddie became sleepy and listless. She drooled heavily. 1 seizure on Monday, 2 on Tuesday and on Weds she had 5 seizures throughout the day. I called Dr. N. and asked for advice. Maddie appeared overdosed and lethargic. Dr. N. suggests giving Onfi time and maybe Maddie is having seizures so will schedule EEG study in 3 weeks. Thursday- Friday 5-8 cluster of seizures within 1-2 hours, Maddie is still lethargic and listless and these seizures don't seem to be like others where she's back to herself. Her eyes appear to be overdosed, called CRS Child neurology and spoke to Vicki (Dr.N. 's nurse). She suggests we take her to the ER and this is where our journey begins.

Friday, August 31, 2012

Emergency Department intake nurse/staff was excellent and saw right away that Maddie was critical & put her in a room immediately without having to wait in the waiting room. We wanted to know if she was overdosed on anti-seizure meds, get her PEMU study, and if she was having a bad reaction to Onfi. Maddie has another seizure while an IV line was placed on her wrist. She was given a bolus of Fosphenytoin ER and Dr. M. pages neurology. Dr. L. (resident/fellows) admits her to 8th floor by PEMU room. Dr. L. attempts to ask questions &learn about Maddie which is great! Maddie's urine appeared cloudy so maybe she has a UTI.

Saturday, September 1, 2012

Dr. A. comes with Dr. L, not much of consult because she appears to be concerned about another patient next door. Linda nurse request/advocates for us and asked that Maddie receive a PEMU study. Dr. A says that she has another kid that needs the study first. Linda states that there's another PEMU room available. Dr. A asked if there's staff for the PEMU, Linda replies that she would be the nurse. Begrudgingly, Dr. A gives the go ahead for Maddie to have a PEMU study. I backup Nurse Linda and state that I want my daughter to have the PEMU study. I thank the nurse Linda for helping us! Dr. A did not inquire about my child. She appears to want to send Maddie home with a UTI. Dr. A made us feel like Maddie and her seizures were an inconvenience. Please Dr. A, make your patient and family feel important and that you want to help and treat them! Don't make it look like you were on call and had to come in over Labor Day weekend. For goodness sake you still had your purse over your shoulder. Geri (EEG tech) also on call comes in later and hooks Maddie up. . Onfi is discontinued and Additional anti-seizure meds are given and Maddie continues to seize. Finally Ativan is given and within a minute she starts hyperventilating, her chest is rising out of her body and she's fighting for air. Linda doesn't know why.

Sunday, September 2, 2012

Resident doctor and attendee Dr. A. come in and order an X-ray of her chest. Her right lung seems plugged up due to possible signs of early pneumonia. She needs to go to PICU. They have a room for her but Geri (EEG tech) has to transfer her to another PEMU free standing monitor so this delays her going to PICU. I'm hoping Maddie does have a UTI or Pneumonia because this would possibly explain her increased seizures. Dr. C. sees Maddie and knows right away that it's the Ativan not pneumonia...so she's put on a ventilator. Within hours, Dr. J. the Epileptologist, pages the attendee doctor that Maddie is have generalized status epilepticus so I'm not sure what all was given to her put she continues to be in status mode. Drs. A & L comes to check on her in the PICU but doesn’t really do anything and nothing is stopping her seizures.

Monday, September 3, 2012

Please continue to pray for our Maddie girl and our family as Maddie continues to battle her persistent seizures. Maddie has been given 5 medications to stop the seizures and now has a breathing tube because the meds have made her too sedated to breathe on her own. She started her 6th medicine this evening. We are hoping & praying that this will stop her seizures. We are anxiously awaiting CT scans, Blood work & cultures results to help determine why she is continuing to have both clinical & subclinical seizure. We are very thankful that she is in very great care of the PICU staff.

Tuesday, September 4, 2012

Dr. C (neurologist) is on shift & appears to be the only one in neurology that knows what he is doing! He actually took the time to learn more about Maddie. He asked if I thought that she was worst since being at CHILDREN’S HOSPITAL. I stated yes. She went from partial seizures to status. He seems concerned that some of the anti-seizure meds may have made her worse so he discontinues four of them. She seems to be able to handle the Versed.

Wednesday, September 5, 2012

Maddie has to be put in a pentobarbital coma to reset her brain. Ok, very scary but we have to try. Dr. C. (neurologist) states during rounds to the residents that she is one of the most complex neurology case that he's ever had because she's been misdiagnosed with cerebral palsy & her brain seizures are getting worst. They have to start from her birth and get her the right diagnosis because some of the anti-seizure meds could actually cause more seizures & death if not diagnosed correctly. First priority is to get her seizures to stop & stabilize her (this is where the coma comes in), then get the diagnosis. She needs to be seizure free at least for 24-48 hours. All of her blood work & cultures do not show any signs of infections so they want to get an MRI, however she's unstable at the moment.

Thursday, September 6, 2012

Better day today: Maddie will be slowing coming out of her coma suppression! She has been at least 24 hours seizure free under the coma suppression. Her brain activities will start to come back and hopefully no seizures as she is being weaned of the suppression med. The coma suppression is supposed to reset the brain. They were able to get some spinal fluids yesterday evening and the preliminary tests showed no signs of infections. The spinal fluids will be sent to Atlanta to tests for some genetics diseases, neurons in the brain & will take about a week for the results. She is stable and will be able to go in for an MRI around 11 am today.

Evening of September 6, 2012

MRI did not show any abnormality in her brain & the seizures did not seem to affect the level of oxygen in the brain and she hopefully will be back to herself. Per Neurology: Diagnosis for her is very crucial because she may have a genetic or metabolic disease that is causing her brain to not turn the right supplement into what it needs so therefore causing her seizures. The next 48 hours will be spent trying to get her out of the coma and trying to see if these supplements & vitamins will give her brain what it needs. Some of the tests will take up to 3 weeks to get back.

Friday, September 7, 2012

Chris was able to stay the night with Maddie last night while I got to come home for much needed sleep and so that I could see my other girls. He will be staying again tonight so that I can spend some time with Marissa and Elyssa this evening. We have a setback today as Maddie started having seizures again while the medical staff was trying to wean her off of Pentobarb (this is the medication that is keeping her seizure free but also in a coma.) She will be kept in the induced coma through the weekend, while the team tries to see if a ketogenic diet will help to control her seizures. Hoping and praying this will work and for answers so that we can see our lovely Maddie’s smiles again. God has been providing us with lots of blessings such as visits from friends at the Children’s Hospital.

Saturday, September 8, 2012

There is not much to update today. Maddie will continue to be in the medically induced coma for the weekend with trials of the ketogenic diet, supplements and steroids along with all of her seizure meds. Dr. T. is the Epileptologist, neurologist is Dr. L. Dr. L. is also a knowledgeable neurologist and takes the time to answer any concerns. Yay for team Maddie! Dr. C. orders 3 days of steroids, he's off for the weekend so attendee Dr. D. discontinues the steroids because chances of infections are higher. I read later in an article of steroids are sometimes used to stop status seizures.

Sunday, September 9, 2012

Right now Maddie is having some seizures through the coma so her seizures meds will be increased. She will continue to be on the ketogenic diet and hopefully will be able to produce ketones which have been proven to help some children with seizures. It may take a few days to figure out if the diet will work.

Monday, September 10, 2012

Dr. C. is back and is disappointed that the steroids were discontinued. He blames himself for not stressing the importance of the steroids. Steroids have about 3-5 % percent chance of helping with status seizures. Tonight Maddie had a bonus of Keppra & injectable Keppra, & bolus of pentobarbital because of the seizure activities & moved Pentobarbital to 2. Her seizure activity seems to have stopped.

Tuesday, September 11, 2012

Maddie is back on a more suppressed coma because of the seizures she was having yesterday evening. Early this morning she had a PICC line with a double lumen put in to reduce her chances of infections. During rounds a few minutes ago, the attending Dr stated to the med students that the longer someone is in a pentobarbital induced coma the higher chance the patient might get sepsis or another infection. Per neurologist: two & 1/2 weeks is typical timeframe for a pentobarbital coma but the average patient will usually be in a coma for 6 weeks for them to get the seizures controlled. She'll be given 3 days of steroids to help with her seizures along with the ketogenic diet to get her little body into ketosis. More tests will be done and sent to the East Coast.

Tuesday, September 11, 2012

We had a very eventful afternoon yesterday, Maddie had clinical seizures through her suppressed coma so to get her seizures controlled a higher dosage of pentobarbital was given to her. (Every time she was stimulated for examples breathing treatment, working on her IV lines or rolling her over would set off seizures.) She is now in a deeper coma which we are hoping will reset her brain to stop seizing. This is somewhat good news because this means that her brain is finally responding to the meds and hopefully will stop the patterns of seizures. She is also being given a small bolus of Ativan before any stimulation is done to her because she seizes every time she is stimulated.

Wednesday, September 12, 2012

It's Wednesday and overall Maddie is at about the same type of level. Her pentobarbital dosage is reduced a little to get her out of the deep suppression coma but she is not ready to come completely out the coma. She needs to have 3 days of steroids and time for the ketogenic diet to work before trying to get her out of the coma. She is not seizing so that is a plus! She has a UTI and is being treated with antibiotics.

Thursday, September 13, 2012

Maddie is stable and neurology might lower her dosage of pentobarbital to wake her brain a little bit. She is showing some mild level of ketones so hopefully this will turn her body into ketosis which hopefully will work to help control her seizures. Dr. C. is having a hard time with the attendee pathologist. Pathology won't do the Gene Dx infantile epilepsy gene panel unless they get a written statement from CIGNA that Cigna will pay because the pathology lab doesn't want to take the lost. The cost is $4800. Is that too high of a price for a life or death situation? If it was their own family member I don't think so. I make phones calls to Cigna to see if they can give me the documentation. They work on Eastern/central time zone so I have to try again tomorrow.

Friday, September 14, 2012

It's Friday and Maddie is resting beautifully in her coma! Her pentobarbital was turned off this morning and since she has so much pentobarbital in her body it will probably take 4 days to wake up her brain completely. We are hoping that her body can go into ketosis asap and the ketogenic diet will work. I called CIGNA case worker, Tina. Children’s Hospital should draw her blood; CIGNA won't pay for researcher experimental test but will pay for this. If a doctor orders it, labs should be drawn right away. Karen case manager for floor has to get medical director & finance director involved. Hours later, pathology agrees to do it because of different attendee but time has flown by already. Earliest blood drawn would be Monday morning at 4 am. I really wished that money issues had not delayed the test. Also I should have been notified of issues. My husband and I are very involved parents and will advocate for Maddie and our other girls. Maddie’s EEG is not looking as good as she is coming out of the coma. Dr. C. informs me in the evening that he is very concerned.

Saturday, September 15, 2012

Things are looking better for Maddie per Dr. C. . Her EEG looks better when she’s awake. He and Dr. T. thinks maybe she might have ESES but are not sure and will have to keep an eye on her EEG during both awake and sleep hours.

Sunday, September 16, 2012
God is so GOOD! Maddie is in ketosis and it appears that the ketogenic diet is working! The plan is to wean her from the high dosages of her anti-epileptic meds so that she can go home with her correct dosages & the ketogenic diet. We are so blessed to have our sweet girl's smiling face. She gave me & the nurses the best smiles today.

Monday, September 17, 2012
Blood is not drawn until 5:30 in the morning. I had to ask Dana one of the night nurses to look for the order. Since the order was special it was handwritten out by Dr. C.. The blood work is sent to pathology but they have to verify, hours later it is processed. Yay..finally all that stress of the test is gone.

Tuesday, September 18, 2012
Today, Maddie is making lots of progress. She no longer has a breathing tube and no electrodes attached to her head! She has some sore spots where the electrodes were placed but she’s still pretty to us. She will be carefully monitored for any respiratory issues for 24 hours and for any clinical seizures for the next few days. She was very tired today but overall is having a good day. We are hoping that she will continue to have good days so that she can go home soon!

Thursday, September 20, 2012
We have a setback again with Maddie's progress. Her right lung collapsed and she is unable to breather sufficiently on her own. She was on a high flow nasal cannula yesterday morning and then put on a BiPaP in the evening to help her breathe. A pulmonary doctor will be evaluating her today. Weaning of her seizure meds are on hold until her respiratory issues are resolved. Despite all of her breathing issues, God has blessed us with lots of smiles from our girl & no clinical seizures. :) Dana works hourly to get Maddie suctioned out so that she does not de-saturation. Kudos to Dana for being an awesome nurse!!

Sunday, September 23, 2012
Maddie is having a great Sunday & is making progress! Her BiPAP was removed this morning & she is now put on a lo-flo nasal cannula. They will continue to monitor her breathing. No signs of clinical seizures so far as her seizure meds are slowly being decreased & the ketogenic diet increased. It's been 24 days in the Children’s Hospital but we are so blessed by God for the caring staff at Children’s Hospital as they help our

Maddie get better.

Monday, September 24, 2012

Dr. C.: "Is this the same kid? This makes my heart happy." She can go home in a couple of days from neurological point to view. She'll wean down on phenobarbital for about a month then will see. He'll mark 4 drugs that she can't have for seizures as allergies. He will call when he gets the test results, epilepsy conference to discuss patients & see who fits best with Maddie & knows the ketogenic diet, needs follow-up in 2-3 months with neurology. So far she is seizure-free with her seizure meds and ketogenic diet. The ketogenic diet is very precise and will require a ketogenic dietitian to tweak and maintain her food. This also means that we can only use products that are carbohydrate-free or contains minimal carbohydrate (this includes lotions, shampoos, and even medicines). Maddie is full of smiles for anyone that comes into her room. She even yells at me when I am not paying attention to her. She is becoming very active and moving her arms and hands more. She will require lots of rehabilitation to get her back on track but she has proven to be such a strong and determine little girl so we know she will be back to herself in no time. The result of her gene test has not come back yet and we may not find out for a few more weeks. We are hoping a correct diagnosis will help with her medical treatment and prognosis.

Tuesday, September 25, 2012

Maddie moves out of the PICU and moves to 8th floor room 8111, no neurology follow-up from floor neurologist or Dr. C. for the day. I know Dr. C. has several intensive care patients so maybe he'll check on Maddie later but more importantly I think that she may be going home soon so I have Elizabeth call him to see about when she might go home. Dr. C. states that from a neurological point of view she was good but a rehab specialist will have to decide too along with floor attendee, Dr. S. when she will be discharged. Dr. C. believes that I may have misunderstood so he will come by the next day. Maddie after 7-8 days of seizure free has a breakthrough seizure 5-25 seconds, moaning & eyes deviated to left, her face was tense at 4 pm. Both the nurse Elizabeth and I witness the seizure and I'm getting concerned now about the seizure.

Wednesday, September 26, 2012

Lisa comes around 12:30 with Ketogenic outline planned out for rest of Children’s Hospital stay and when she is actually discharged. She will require some tweaking of the diet so Maddie will have to remain in the hospital for a bit longer. Maddie has had No bowel movements yesterday...but had lots of diarrhea the last 3 days. Her electrolytes are messed up so they are going to give her potassium through her g-tube. Could this maybe be why she had a breakthrough seizure? The Nurse Elizabeth states that Maddie may have had a seizure around 9 but is not sure because the PCT, Aubry witnessed it. I'm getting a little concerned because there's no neurologist following her. Dr. C. came by about 6pm & stated he spoke to 8th Floor doctors & had discharged her from neurological point view. I ask Dr. C. about marking the seizure meds that she can't have and also emergency meds for when we are at home. I also informed him about the seizure from yesterday. I don't want to bother him because he is mainly PICU neurologist....But I feel like a neurologist should still be following her because later she has another Seizure @ 7:08 pm, 20 seconds fixed eyes stare & the tweaking of her ketogenic diet. I'm very worried that she may seize again and then what? I'm not sure if Dr. C. thinks she's going to go home soon or if I've been to pushy about getting her home but I know now Maddie will have to be here longer because of the Ketogenic diet & her electrolytes being off. Dr. C. is a great doctor, he definitely is topnotch in the PICU and helped to save Maddie's life but I still feel uncomfortable about not having neurology on top of Maddie's neurology because of the past weeks in the PICU and being in a life threatening situation, on a Ketogenic diet (that is still being tweaked and treated like another medicine) & having been in a medically induced coma. I felt more uncomfortable as the night resident Dr. H. (resident dr) suggested maybe an EEG.

Thursday, September 27, 2012

I emailed Lisa about Maddie's Ketones and seizures. Her Ketones are at 3+, could that possibly have caused the one 20 seconds seizures last night? I inform the resident Dr. D and she will let Dr. C. know. She also doesn't know what to do. I take all of my concerns to the attendee Dr. S. and he agrees with my neurology concerns. He's not sure who Dr. C. spoke to but Dr. S. is going to find out and also get a neurologist to follow Maddie for the rest of her stay. He calls me later and informs me that Dr. L. (neurologist) will come by either tonight or tomorrow to follow Maddie. I informed Dr. D. of this and she sighs with relief. She stated that would help them too if a neurologist was following Maddie. She had spoken to Dr. C. about the seizure but he is hoping that her seizures are isolated incidences. Both Drs. D. and S. are hoping to discharge Maddie from the hospital on Monday. In the evening, there is no Dr. L. according to my mother in-law.

Friday, September 28, 2012

I heard back from Lisa via email and she is going to adjust the ketogenic diet. There can be breakthrough seizures so this is not uncommon. In the mean time, I'm still sick so I'm at home. My mother in-law states no neurologist has come by as of the morning. I had asked her to inform the doctors to call me. Dr. S. calls me and asked me if Dr. L. came by last night. I told him no and he stated that Dr. H is now the neurologist on duty and he hopes that she will come by to check on Maddie today. My mother in-law informs me that a resident Dr. L. came by at 11:20 am to talk to me and my mother in-law gave her my cell phone. I do not get a phone call. It's 10 pm and a neurologist still has not come to see Maddie. I don't understand the neurology world but I can't believe that CHILDREN'S HOSPITAL will let a child that had status epilepticus and had to be put in medically induced coma and still not knowing actually where she's at seizure-wise (clinically or sub clinically), whom had spent 23 days in the PICU and 29 days total at CHILDREN'S HOSPITAL go for having an incompetent neurologist Dr. A to great Neurologists and Epileptologists (Drs. C., L., and T.) to incognito Drs. L. & H. all in 29 days at THE CHILDREN'S HOSPITAL. I'm not sure if it's a staffing issue or miscommunication or misunderstanding but with all the trauma and scary moments for my daughter, Maddie, I do not want to deal with residents or incompetent/incognito neurologists that will do my daughter more harm than good. I truly do not believe that I am being unreasonable to have such high standards of quality of overall health care of my daughter while she is a patient of THE CHILDREN'S HOSPITAL or a future patient.

Saturday, September 29, 2012

Maddie has had a good weekend and has been seizure free over the weekend! Her ketogenic diet is what is holding her up from being released from the hospital. The dietitian is tweaking her formula daily and hopefully Maddie will tolerate the changes being made to her diet. We are so thankful and blessed that her Gannie was able to stay with her for the last two days. I'm back with my girl and love seeing her precious sweet smile. We've been exploring the hospital in her wheelchair and have had lots of love from our friends who visited us today including Maddie's BFF from her preschool days. This is day 30 of Maddie's hospital day but I can't complain…the other day, I spoke to a mom who's daughter had been in the hospital for 7 months battling cancer and I'm happy to note that the little girl is doing well and was released the next day. God is truly GREAT!

Sunday, September 30, 2012

It's Sunday and Maddie so far is seizure free since Wednesday evening. We still haven't seen a neurologist but I'm not as worried because she is not seizing. Dr. D. and Dr. S. will be trying to get all of her prescriptions, ketogenic diet, and equipment so that she can go home possibly tomorrow. Maddie is on a modified Bolus feeds and we are hoping that she'll be able to tolerate the feeds so that she can be released from the hospital soon. Lisa is scheduled to meet us at 10 am tomorrow to go over discharge plans. Maddie is a happy girl.

Monday, October 1, 2012

It's Monday and I'm waiting to speak to Lisa the Ketogenic Dietitian. Dr. S. and 8th Floor nurses are not sure how to do her bolus feedings. We were also waiting for Cindi, case manager about her formula, prescriptions and supplies before going home. Dr. H. finally came to see Maddie and I. Didn't really act like she knew why she was consulting until I told her my concerns. Says she is okay with her going home because Maddie has intractable seizures and will be having seizures. If clusters of seizures 5 within a couple of hours then give her diazepam and a bolus of 750 ml of Keppra and then call Neurologist on call if still seizing. Lisa came and discussed the discharge plans and stated to do bolus feeds and water fluids. She will email me a clean sheet. I am worried still because Maddie continues to have more 2 seizures and is very sleepy. Dr. Solomon calls to check on me and to see how everything is. I mentioned the seizures to him and he asked me to ask Machelle to page Dr. H. (to see if she should still be discharged or not). Machelle never gets a call back from Dr. H.. I finally realize how unimportant or unique my daughter is to Dr. H.. Since Friday, Dr. S. and I have been trying to her to come in for a consult with Maddie and me. I guess this is the neurology world and how they look at my daughter and her epilepsy as just another number, another seizure, another special needs kid who is most likely is going to die from unexplained death from seizures…just another number and why are we (parents & kiddos) inconveniencing them. Neurology may be used to this thought process where they see it every day so they lose that compassionate nature so that they don't become emotionally attached or for whatever reason. I realize then that there's going to be unanswered questions, seizures and scary moments but Maddie needs to be home where she is loved and will be cared for to the best of my and my husband's ability. I'm not sure how long we will have this sweet girl and this precious gift from God but we will kiss and hug every chance we get and love her always.


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