

# Kyle's Keto Story



Montreal, August 27, 1994

We planned on starting our family  
right away and it worked!



Kyle was born May 10, 1995 Pregnancy was normal and he passed his newborn tests with flying colors. Over the next few months Kyle met all milestones.



It wasn't until he was 9 months old when we noticed his head nod "yes" 3 or 4 times over a span of a few weeks.

After mentioning this to our paediatrician, immediately the next morning we had an EEG at the Montreal Children's Hospital.



To our shock the neurologist informed us Kyle was having seizures, he then said they needed to test Kyle to look for any malformations within his brain, perhaps that would be the cause of the seizures.

After the nurse took Kyle away, it was then my husband and I found a stairwell & cried in each other arms. Allowing the newly diagnosis of our son to sink in...



Thankfully these immediate tests came back normal. Kyle was given anti epileptic medication and admitted for observations & further testing. We called our families & shared the sad news. Of course we were not prepared for a hospital stay, thankfully family members brought us a few things. We ended up staying for 5 long days. I remember the heavy metal hospital crib. The sides in the up position seemed very high. I particularly hated the clicking sound the bars made separating me from Kyle at a time when I needed to be closer to him, and him closer to me.

Eventually he was diagnosed with head drops. We were sent home with medication, follow up with our pediatrician and hopes that this would fix everything.

Well this wasn't the case, we watched all progress he had made until that point slowly diminish. No longer crawling, no baby talk, and his interaction with us fading. Side effects of the medication were either hyper-active or he was like a zombie. His seizures began to be more frequent so we changed medication and added more medication. No improvement. When his seizures became one every minute, I called the doctor and I was instructed to combine the different meds that we had at home to see if there would be any effect. Again no improvement.

Our neurology nurse recommended us to purchase a helmet for Kyle to protect him from the dozens and dozens of head drops he was experiencing every hour. The helmet was made by a mom, who sold them from her home. It's sad in a way that she makes them, but of course I am forever grateful.

Shana, the dog in the picture, was a welcomed visitor to our home. Kyle loved the gentle attention from her.

We were informed he would need physical, occupational and speech therapy and went for initial assessments within the hospital. He was behind for his age and a schedule was set up for his therapy sessions.



One afternoon, Kyle was propped up on the floor playing with his cousin & Aunt who were visiting. Kyle would have a seizure, his head would nod and this would make him lose his balance & I would have to correct his posture. All of this would happen in about 2 seconds because the episodes were so quick. We all watched silently for a long time, while I would prop Kyle up time & time again after every seizure. This went on for about 10 min. Emotions were very raw, it was hard to digest everything that had taken place over the last 6 weeks. Our little guy was only 10  $\frac{1}{2}$  months old, and this was not looking good, when was this going to end?

A family member heard of a segment on Dateline about a diet that helps people with epilepsy, she immediately phoned me and we tuned in as soon as it aired in the Montreal area. A Hollywood producer, Jim Abrahams, has a son, Charlie who was diagnosed with epilepsy. Their story is quite similar with seizures not controlled by medication. Jim started to do his own research and discovered Johns Hopkins Hosp. treated kids with epilepsy using the Ketogenic Diet. Charlie was immediately put on the diet and his seizures were completely controlled. Jim wanted to get the word out that there are other alternatives if medication did not work. He & his wife Nancy, were on Dateline three times telling everyone their story. These are one of the segments we watched.  
THANK GOODNESS FOR JIM & NANCY!

Of course we were on the phone the next day with the Montreal Children's Hospital, and were told they do administer the diet!

Meeting our neurologist, he informed us that the diet does not really work. That did not sit well with us at all. Clearly medication was doing nothing for Kyle and if there was any chance for him to stop seizing then maybe the diet was our answer.

After long discussions with the neurology nurse & dietitian, we decided to try the diet, with hopes of diminishing Kyle's seizures. Our team was assembled; neurology nurse, dietitian and us to administer the diet on the 27<sup>th</sup> of April '96. We were admitted to the hospital for 5 days starting with a 2 day fast - that was really tough not feeding our 11  $\frac{1}{2}$  month old. (Our team wanted to wait for Kyle to be as close to his first birthday as possible, as Johns Hopkins Hospital had not introduced the diet to a baby).

Over the next few days we gradually introduced the diet to him with an egnog recipe.

While in the hospital our dietitian (our HERO!) worked closely with me to instruct how to calculate his meals according to the figures (fat/(pro+carb) ratio) she would provide us. We hand calculated everything - remember, there was no internet!

After 5 days we were sent home from the hospital to continue the diet and to record everything!! From ketones, seizures, weight, mood, bowel movements, medication...

Meals  
3/12 Sabri

Supper

1.63 = .54  
3  
100 = 3.13 r = 17.25 cream .39 6.04  
X .54 .56 17.89 .40 6.26

100 = 7.05 r = 7.66 strawberry 100 = .6 r = .04  
Y .54 .56 7.94 7.66 X .05

100 = 6.4 r = 8.44 squash 100 = .64 r = .05 100 = 4.87 r = 100 = 7.7 r = .05  
Y .54 X 8.44 X .54 .56 11.5 X .05

100 = 3.1 r = 6.74 chick 100 = 3.6 r = .24 100 = 2.9 r = 7.2 100 = 1.5 r = 1.5  
X 2.05 6.74 X 6.74 X .23 X 2.05 6.9 X .45

100 = 7.19 r = 7.51 w/melon 100 = .63 r = .05  
X .54 X 7.51 X 100 = 10.5 r = 5.14 100 = 1.5 r = .05  
5.14 X

100 = 8.38 r = 6.44 cantelope 100 = .88 r = .06 100 = 2.9 r = 100 = 3.2 r = .05  
Y .54 X 6.44 X X .54 X 3.2 X

100 = 12.7 r = 12.46 100 = 3.19 r = 3.60  
X 2.09 X 17.06 X 17.06 X .54 X 12.16 X 3.1  
100 = 2.56 r = .31

100 = 11.42 r = 17.42 hotdog 100 = 2.0 r = 3.83 12 X  
X 2.09 X 17.42 X

100 = 4.3 r = 10.46 100 = .89 r = .11  
X .54 .56 12.7 X X .12

cream 17  
strawberry 8  
squash 12  
chick 6  
milk 7

cream 17  
strawberry 8 on cantelope 6 on req 3.5 on peach 5  
squash 8 on turnip 11 on tomato 13 on carrot 5  
chick 7 on bologna 16 on dog 17 on beef 7  
butter 17 butter 13 butter 13 butter 17

Yes it was tough at the beginning of the diet, finding the correct ratio that kept him in ketosis, calculations for his ratio, weighing his food & pureeing it, took many hours a day to prepare his meals. The amount of food he was allowed to have was very little but we kept on fine tuning the diet to meet his exact needs (4.5:1).

I remember spending the entire day in the kitchen preparing meals for 3 days because of upcoming medical appointments - thank goodness for Tupperware!



Our team was 100% dedicated to making this work with us. Did I mention there were no cell phones at the time? 24 hrs a day I was able to "page" our dietitian (if you don't know what "page" means, I suggest you Google it!) and she would immediately return our call! Talk about team effort!

In 1996 the Internet was not widely available in homes and nutritional facts, specifically fat, protein & carb were not printed on products. Whenever I needed to create new meals, I had to use a phone book to look up company telephone numbers asking for the nutritional details and only then start putting these numbers into his ever changing ratio. If he gained a bit of weight, his calories changed, if he lost too much weight, the calories changed, if ketones stayed too low or high the ratio changed. Everything was hand calculated.

One day our dietitian told me to skip a lunch because Kyle's ketones were not high enough. I put him in his stroller and walked and walked. I bumped into our neighbor and was asked how Kyle was doing, our neighbor had tears in his eyes when I said I had to skip lunch again today and that is why I am walking around all afternoon. Yes it was tough. The diet was tedious and yes it was time consuming but what was the alternative? We saw no seizure improvement while on meds.

Now our story becomes a bit brighter!

Celebrating Kyle's 1<sup>st</sup> Birthday - on the diet for 12 days.

I had to be really creative when it came to making his 1st Keto Birthday Cake! A little imagination using the correct ratio, turned out great. I used cream cheese, whipping cream, frozen butter, strawberries and sprinkled with vitamins - he enjoyed it very much!

After 3 weeks of introducing the diet, we slowly started to see his seizures diminish! Within 6 weeks he was seizure free! We were really excited and hopeful for total seizure control.



Blood work, neurology, dietitian reviews were a regular part of his treatment along with the diet.

Kyle started to improve with his awareness, mobility & communication.

In the fall of '96 he started with physical therapy and occupational therapy.



Eventually we felt more comfortable with the diet and we slowly let Kyle begin to feed himself. After all, occupational therapy said he needed to work on his fine motor skills - what better way than picking up frozen cubes of butter which he loved & using a spoon was very amusing to him!

In this photo Kyle is eating whipped cream.



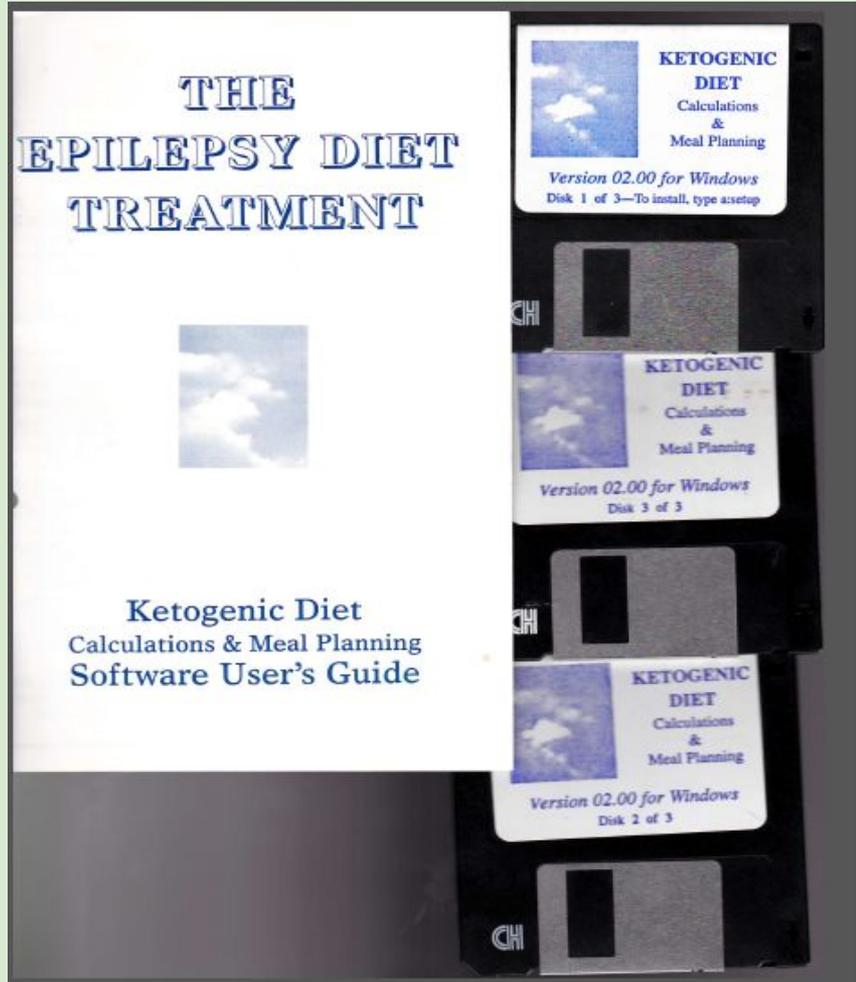
After a year on the diet, we were guided by neurology to slowly wean him off all seizure medication. Still no seizures! I cannot believe that our first neurologist said the Ketogenic Diet did not really work! We were over the moon with the results!

Our days were busy with therapy sessions, meal preparations and medical appointments but having no seizures was everyone's goal for Kyle and our team effort was paying off big time!



Finally technology was advancing :), yes those are floppy disks!

I purchased software for meal planning & calculations, Yay!! No more calculating by hand.



At the request of families on the diet in the Montreal area, a support group was formed. Knowing we were not the only Keto family made a difference. We shared the same frustrations (meal ideas), challenges (brand of cream cheese discontinued) and most important we were able to share some good laughs!

Our families and friends were a big part of taking care of Kyle. They were always around to help make meals, distract him when he refused to eat, drive us to appointments or just allow my husband and I some time to get away.

My niece, who is a year older than Kyle, was sitting right beside him one day as I was feeding him his Keto meal. She was watching me open my mouth to show Kyle, as I was about to feed him, she opened her mouth and I ended up feeding her a few spoonfuls! Of course I worried that Kyle was not getting his full ratio but in the end it did not make a difference, we still laugh about that today!

## The Keto Klipper Roseway, N.S.

We went on many family Keto vacations. Planning in advance made things smoother for us. Knowing ahead of time, what brand of cream cheese and cream were available in the area we were staying so I could calculate it into his meals. We made Keto part of our daily lives, we had to in order to make it work!

While in Nova Scotia, my husband named the little boat "Keto Klipper" which we filled with water and Kyle would play in it daily!



Celebrating Kyle's 2nd  
Birthday with another Keto  
cake and still seizure free!



## Enjoying a Peanut Butter Puff!

Kyle was on the diet for 1  $\frac{1}{2}$  years when acidosis became an issue. We were referred to renal who tried to control it with sodium bicarbonate. For 2 months we tried different doses of bicarb, at one point he was on 15 pills a day. Still the acidosis was an issue. Inevitably there were signs his body was ready to come off the diet. For example, height was affected and hair & nails hardly grew.



Fall 1997 at 2  $\frac{1}{2}$  yrs old, with the guidance of our team, we slowly weaned him, watching him very carefully for any signs of seizures. Still nothing! He adapted very slowly to a regular diet over the next few months and his acidosis corrected itself.

We paged our dietitian during the time of introducing new foods, she was holding her breath while returning our call, and was relieved to find out that we were sharing with her Kyle's first experience eating ice cream at Dairy Queen!



Kyle's physiotherapist worked tirelessly with him because he was afraid of walking. November 1997 the therapist told me to leave the room and do not come back for an hour. I roamed the hallways of the hospital for a long while until I heard a toddler crying. Recognizing the cry, I started to walk towards the physio department and saw Kyle walking down the hallway for the first time on his own!! Kyle wanted to find me so the physiotherapist forced him to walk. Of course I was very emotional as he walked into my arms for the first time!

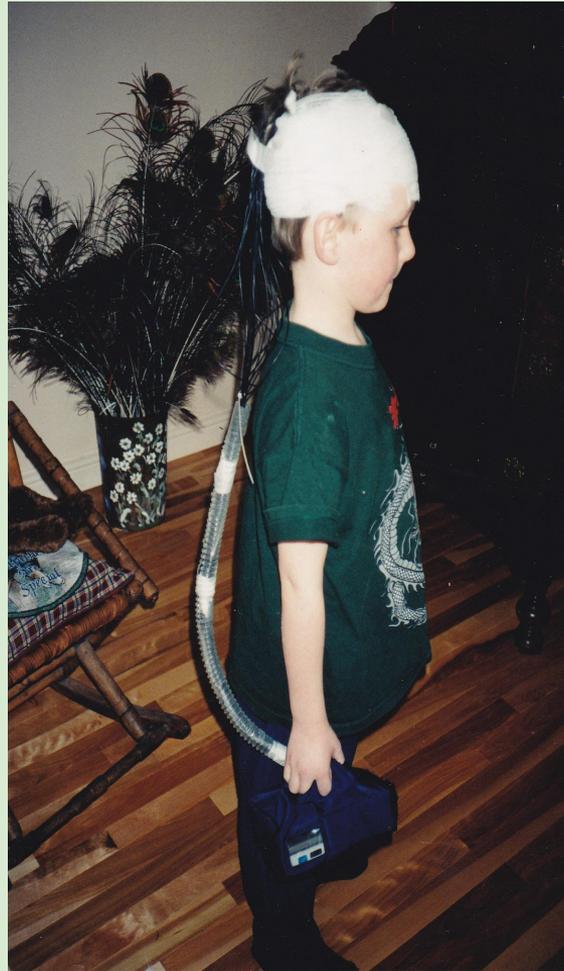
We continued with speech & occupational therapy. He caught up for lost time. His appetite grew as much as his height & weight did!

Our follow ups at the hospital became less frequent.

In grade 2, Kyle's teachers were noticing he was easily distracted & unable to focus, Dexedrine was prescribed to help him be more attentive with his school work.

While in grade 3, his teacher thought she saw a seizure, we immediately notified his doctor and Kyle was set up with a telemetry for 48 hrs. He went to school and teachers were told if they thought they saw activity to press a button. Thankfully no button was pressed - yay this was a false alarm!

Grade 5 Kyle was assessed by psychologists and was diagnosed with a learning disability. An individual education plan (IEP) was setup for him and he began to enjoy school just a tiny bit more, at least that's what I like to believe :)



Fast forward to today 2016, Kyle remains seizure free at 21 yrs old, drives the family car, enrolled in college courses and has a part time job. He weighs 175 lbs, is taller than Mom and yes, has a hefty appetite! He is captivated with Comic Books, Marvel & DC Movies, he has a youtube channel where he reviews the latest..... If you ask Kyle a question about the world of comics - be ready to hear an earful!

Life is good.

