

# Wyatt's Story

**A Father's Retelling of How the Health System and one of our Nations Best Hospitals Failed a 9 Month Old in Need of a Liver Transplant**



**By Corey Leamon**

## Meet Wyatt, aka “Pie Man”

Wyatt Reese Leamon was born September 2<sup>nd</sup>, 2007 in San Diego, California... a happy, healthy baby that lit up any room he was in. His smile and laughter was infectious and the light in his



eyes when you played with him was so bright, you would think angels were looking right through him at you. The amount of love our family felt for this little guy who we affectionately called “Pie Man” could never be measured.

It was actually his older brother Parker (who turned 3 on May 2<sup>nd</sup>, 2008) whose young vernacular led to the nickname “Pie Man”. You see, when Wyatt was still in his mother’s womb, we had a lot of trouble naming the little guy. I absolutely loved the name of “Wyatt” due to it’s deep history of the Wild West and one of the most famous western figures of all time, Wyatt Earp and it was

literally the weekend before he was born before my wife finally gave in and agreed this would indeed be his name.

One of the other reasons I liked the name is because I am somewhat of a tech geek. I thought the coolest nickname for him would be “Wi Fi” and when he was born I began using that name almost immediately. But Parker was just 2 ½ years old at the time and as with most toddlers, they don’t pronounce certain things properly. So when we asked him what his brother’s name was, instead of saying “Wi Fi”, he answered “Pie Pie”. Shortly thereafter, my wife put her own spin on that name and we began calling him “Pie Man”. The name stuck and it was such a perfect nickname for him (I used to joke that he was a little “Punkin’ Headed Kid” and therefore, he was “Pumpkin Pie”).

For 8 full months, our little Pie Man brought us so much joy as he grew from a newborn into a little infant boy who was on the verge of crawling and eating solids. He was healthy, happy, adored his brother and our family was complete and about as perfect as it could be.

## A Little Boy Gets Sick

Around his brother’s birthday on May 2<sup>nd</sup>, 2008, both Wyatt and Parker had come down with some sort of cold and what ended up being an ear infection. Parker’s cleared up pretty quickly but Wyatt’s continued and we could tell he was agitated by something. We took Wyatt to the doctor on May 5<sup>th</sup> (Children’s Primary Medical Group in Escondido, CA) where they prescribed him Amoxicillin for his ear infection (and anti-biotic similar to Penicillin).

A few days later (approximately May 7<sup>th</sup>), Wyatt seemed better but he started displaying signs of severe diarrhea. His stools were large, bright yellow and very thick in texture (like they were full of



mucus). This continued on for several days when we took him back to his doctor who really didn't seem concerned. They checked his ear infection which had dissipated and recommended we stop giving him the antibiotics.

But after a week or so of continued bouts of this diarrhea problem not going away, we began to be concerned and once again, we took him to the doctor. Again, we were met with a lack of concern, they even told my wife "we're getting lots of kids with diarrhea". My wife remarked "for over a week?" They finally agreed to test a stool sample. A stool sample was given on May 19<sup>th</sup> and May 20<sup>th</sup>.

Finally, on Wednesday, the 21<sup>st</sup> of May, we started noticing some severe agitation in Wyatt. He was not sleeping well and his diarrhea persisted. We also noticed he had developed a rash of some sort... his face and body were covered with little reddish spots. We took him to the doctor one final time where they first lectured my wife on feeding him solids instead of just breast feeding him which had nothing to do with the current situation. Upon leaving the appointment, Trisha received a call from the doctor's office stating that his stool came back positive for C-Diff virus (which often happens with people who take antibiotics). They put him on Flagel (an antibiotic which treats C-Diff) but after taking his first dose, he began to throw it up severely any other time we tried. He also could not go to sleep and we stayed awake the entire night trying to console him to sleep. It was about 3am when we decided to take him to the emergency room. At that moment, he had fallen asleep finally and we promptly took him when we all woke up the next morning.

### **Admitted to the Hospital**

On Thursday, May 22<sup>nd</sup>, Wyatt was admitted to the emergency room at Rady's Childrens Hospital where his rash started to expand into splotches all over his face and body. He was in pretty awful condition and we were certainly frightened.



Even though there weren't any visible signs of liver failure (such as jaundice), the ER technician thought he would run a liver related panel. Unbelievably, Wyatt was near liver failure. They acted quickly to get him admitted to the hospital where for the next 8 days, they battled what seemed to be some sort of virus that was attacking his liver. During the course of the treatment, Wyatt reacted to one of the drugs they gave him. He swelled up like a balloon in his face, neck, throat and lips. During a short period, we spent

time in the intermediate critical care unit to closely monitor his breathing. By the end of the week, we were back on the floor with no diagnosis and the doctors were stumped. They believed it was viral but did not have any positive lab work to prove it. Another theory was that he was reacting from the Amoxicillin (referred to as DRESS syndrome).

On Thursday the 29<sup>th</sup>, Wyatt underwent a liver biopsy which resulted in a 99% sure that it was viral and not an auto-immune issue (which is when your immune system turns on an organ in your body and begins to attack it). They felt that they should give him a blood transfusion on Thursday to help him recover from the biopsy and come Friday, he was a happy, bouncing boy and his rash and the swelling incident were a thing of the past. At that time, they pretty much felt everything was under control and even though they didn't have a diagnosis yet, they released him to come back home with orders to come in for some blood work on Monday.

Unfortunately, our happiness and relief was short-lived. Sunday he seemed very lethargic (a sign of liver problems) and on Monday (the 26<sup>th</sup>), he was readmitted after some required blood work showed his numbers were still elevated. Coupled with his lethargy, the doctors were very concerned.

## Diagnosis and Treatment

During the week of June 2<sup>nd</sup> to the 6<sup>th</sup>, the doctors changed their minds regarding what the problem with his liver was. They reversed their position on the biopsy and told us that with his "INR" numbers (which measure blood clotting) not improving and two positive LKM antibody tests, they now believed that he had an auto-immune issue. For some unknown reason, Wyatt's body was now attacking his liver as if it were a foreign object such as a virus. The treatment for this was to use a decent dose of steroids over the course of a few days to try and suppress his immune system from attacking his liver. This treatment failed. As our doctor so eloquently put it, "the disease just laughed in the face of steroids". Because of this failed round of treatment, they began discussing with us what they believe was an accurate diagnosis... Autoimmune Hepatitis Type 2. Type 1 is usually treatable with steroids and can be quickly turned around. Unfortunately, Type 2 is much more difficult and is resistant to steroids and other treatments. It was around this time that they started planting the seed that Wyatt may need a liver transplant.



Over the weekend, they tried one last treatment of an immunosuppressant called Cyclosporin. This medication is often used in patients who receive liver transplants and works similar to steroids where it's supposed to suppress the immune system. This too failed. Not only did it fail, but for the first time, Wyatt was starting to show significant signs of being really sick. Over the weekend his health declined rapidly and he went from an overall happy normal baby (from a personality standpoint), to sleepy and groggy and when awake very agitated and inconsolable.

On Monday June 9<sup>th</sup>, we were told by our doctor that his condition had worsened significantly and they in fact listed him as a "Status 1A" patient which is the highest priority designation a liver patient could be. We also had a pretty heated conversation with several of the doctors at Rady's (including Dr. Newton, Dr. Wang and Dr. Kahna) and insisted that they begin the process of screening myself, my wife and my sister-in-law as potential live donors and they did indeed move forward in blood typing both of the women (I had to leave prematurely to take my son home).

That morning, we were also told some additional disappointing news. Our insurance company would not approve the transplant at Rady's in San Diego. Our entire family would have to be uprooted to Los Angeles which frightened us because not only was it scary from a logistics standpoint, but we were concerned that the medical team in UCLA would not know Wyatt nearly as well as the staff at Rady's. The CEO and/or the CFO at Rady's attempted to negotiate with my health insurance company to keep him there for the procedure, but their attempts were rejected and the transfer was set for the next day.

Eventually, after a discussion with Dr. Newton who knew Wyatt best and was our primary care doctor for the majority of the time there, we felt good about the transfer and felt we were heading to UCLA to get a liver transplant based upon the opinions of our doctors at Rady's. After all, Dr.

Kahna, Rady's head transplant surgeon summed it up best on Monday, June 9<sup>th</sup> during our discussions... he told us that if he had a liver that day, he would transplant immediately.

### **Move to UCLA Medical Center**

On Tuesday, June 10<sup>th</sup>, Wyatt was air-lifted to UCLA Medical Center where we believed we would be heading for a transplant pretty quickly. The reason our insurance company refused to allow



the transplant to happen at Rady's in San Diego was due to them not being a "Certified Center of Excellence". On paper, it sounded like this was certainly the best move because UCLA Medical Center is one of the top hospitals in the nation and they definitely are one of, if not the best liver transplant center on the planet. Unfortunately, this move may have sealed my son's fate.

Upon arriving to UCLA Medical Center, it was certainly a different atmosphere compared to that of Radys. It was a much bigger facility with a chaotic PICU (Pediatric Intensive Care Unit) teeming with activity. And for the first time, we

accepted the fact that my little boy was going to receive a life-saving operation that would affect his life (and ours) forever.

A few hours after meeting up with Wyatt at his bedside in the PICU, Trisha and I were called into the conference room to discuss his health. It did not take long for us to get a sense of extreme confidence in this team and it was at this meeting that we believe a chain of events began that led to my son's death.

### **No Transplant, More Treatment**

During our discussion with Dr. Mehra regarding Wyatt's treatment, we were actually filled with a lot of hope and it was, at the time, a large breath of fresh air. To her, Wyatt seemed to be in much greater shape than what we were led to believe by Rady's and she even talked about how

he probably should be moved onto the floor because as she put it, "the ICU is for really sick babies!". "The Floor" is a term used to describe the rooms outside of the ICU and is a less intensive care area where the nurse to patient ratio is less (the ICU is 1 nurse for 1 patient while the floor is usually 1 nurse for 4 or 5 patients) and there is not a continuous monitoring of a patient's health by a nurse in the room (just machines). We were completely blown away. We were terrified of a very scary surgery, the liver transplant, and here, these doctors were almost laughing at the thought that he would be transplanting right away (keep in mind, his numbers were severe



enough, even this early, to merit the "Status 1A" listing on the donor list to receive a transplant). In this initial meeting, we made it very clear that the one thing we requested was that they didn't

lose sight of the two weeks of history that we had in San Diego. We didn't want them to look at him as they saw him at that moment, but rather, to look at him in relation to his decline since the time in San Diego to now. Sadly, our fears were valid and we now believe that they did exactly what we told them not to. They saw a chubby healthy boy with some bad liver lab readings, not a very sick child in need of a liver transplant.

In the meantime the medical staff continued to remind us of their experience level and how successful they've been and they told us that Rady's didn't do enough to treat the disease so they wanted to do that more aggressively. Again, keep in mind that this very day, we were told Rady's in San Diego was ready to transplant.

So with some questioning of Rady's for listing him on the national donor list in the first place, the doctors moved forward with a similar round of treatment in hopes of saving his current liver. They believed that a transplant should only be the very last resort, but what we didn't know at the time, and what we know now, is that a very "last resort" may be too late because of the way the donor list and the entire system is run. They instantly removed him from the "Status 1A" list in San Diego and added him to the list as a "Status 7" which essentially gave him no priority to receive an offer for a liver.

Over the course of that first week, they repeated much of what Rady's tried... steroids (with some additional medications) in bigger doses for a longer period of time and just like in San Diego, Wyatt continued to show solid signs of strength on the outside even though, slowly but surely, his numbers continued to decline. For the first several days of treatment, even though his numbers were not really improving, they continued to tell us that he may end up on the floor. As I look back now, I realize that this was the beginning of a pattern of underestimation for how sick Wyatt really was on the part of his medical team.

### **Wyatt Begins to Decline**

By the weekend, the doctors admitted that the steroids were not working for him. But again, rather than moving forward with a transplant, they decided not to list him as "Status 1A" and to instead apply a bigger dose of steroids. Saturday, the 14<sup>th</sup> and Sunday the 15<sup>th</sup> were very difficult days. Wyatt began showing signs of extreme agitation and was very difficult to console. We



could tell that he was a bit different as most of his playfulness was gone. We continued to inform anyone and everyone (nurses, PICU doctors, liver doctors, etc.) that we were concerned and we were told that this could be a result of the high dose of steroids he was receiving, or that it could be a result of him just being sick of the hospital. In essence, they really didn't know with any certainty why he was acting this way (after all, being an infant, he wasn't able to communicate his pain or frustration to us).

On Monday the 16<sup>th</sup>, Wyatt began showing a new type of agitation. He would make a strange cry, flail his arms almost uncontrollably, and for the first time, when he looked at us, it was as if he didn't recognize us. He began not wanting to rest on top of us (which he had done pretty much the entire time we were at either hospital). He would be agitated and flail around for a minute, and then suddenly drop his head and sleep for 30 seconds. Then he'd wake up and it would happen again. This just continued on and on until he was so exhausted he would fall asleep. It was on this day that Dr. Sue McDarmid finally came around to discuss

transplant as the next course of action. Amazingly, during this conversation she admitted that she was hesitant to list him that afternoon and thought we might wait until morning. She mentioned it was an ethical issue for her because he looks so much better than other patients waiting for a liver. She also stated that it would be hard for us as parents to understand this, but that she had to make the decision to place him on this list when there may be other kids who are intubated and “visually” worse off. Keep in mind, his liver lab numbers justified this 1A status, but his physical appearance didn’t (according to the UCLA team). We continued to voice our concerns that Wyatt was worse than he looked and finally, by the end of the conversation, she came around and decided to list him “Status 1A” to start receiving offers. I think this is another perfect example of the lack of true vision for how sick Wyatt was. How they could even consider waiting until morning to list him was beyond what we could comprehend. We were at least fortunate she came around and we did not have to fight that battle at that time.

By Tuesday the 17<sup>th</sup>, Wyatt was not interactive, flailing his arms even more frantically and essentially, he was completely out of it. It was excruciating to see him this way. We received some good news in that a liver offer had come in so that had us hopeful. Unfortunately, it couldn’t be split for him (it was too large) and we had to wait for the next one. I distinctly remember Dr. McDarmid telling me that it was ok and that we were going to be “picky” with the liver offers at this time. Since she had so much experience and seemed so confident, it was hard for me not to trust that this was the right course of action even though in my heart I was deeply concerned about Wyatt’s mental state. In fact, on several occasions, the RN staff and physicians told us that the agitation and arm/leg movements were “part of the course of liver disease” and once we transplanted, these things would “go away”.

Wednesday the 18<sup>th</sup> produced the same result with a 2<sup>nd</sup> liver offer coming in, but “a no go” due to size. And while we didn’t receive a liver, we did see more signs that our doctors and care staff were underestimating Wyatt’s decline in health.



The morning of the 18<sup>th</sup>, my wife was greeted with more uncontrollable agitation by Wyatt which prompted her to request help in calming him down. This was also the last time Wyatt would be fed by his mother from her breast, something we were often told leading up to this was something to look out for

(change in eating patterns). During the chaos and emotion of the morning, we were fortunate that my sister-in-law walked in to catch a very inexperienced nurse (he was a couple days on the job working on a critically ill patient in a PICU setting... how could that be?) beginning the process of giving my son Tylenol (signed off on by one of the PICU doctors somehow). This was truly unbelievable. Anyone remotely familiar with the liver process knows that acetaminophen can be deadly. In fact, acetaminophen toxicity is the number one cause for acute liver failure in the United States. Yes, you read that right. They were about to give my son, who was slowly dying of liver failure, a drug that causes more liver failure in the US than any other.

There were several other instances that illustrated our nurse’s inexperience that day including giving him a dose of lactulose (a drug to help him poop) when he specifically was told not to, and a misunderstanding regarding the number of doses of antibiotics he was supposed to give my son that day, but in the end, we can’t help but wonder how such an inexperienced nurse is assigned to such a sick patient. We certainly discussed our concerns with the doctors and the charge nurse who admitted that the admin who assigned him to us made a big mistake.

In addition to our issues with the nurse, we continued to experience a high-level of tension for how well our son was mentally and this insistence was met with resistance by the doctors. After initially being rejected about that assumption, the doctors finally caved a couple hours later and moved forward with a CT scan (as they prepped Wyatt for the move downstairs to get the CT scan, another nurse had to actually remind our rookie nurse to connect Wyatt's fluids).

The result of this scan was normal, which provided temporary relief but which ultimately became a sick sort of foreshadowing for what was to come.

## Live Donor Option

Even though we saw marked difference in Wyatt beginning on Monday, the 16<sup>th</sup>, it was not until Thursday, the 19<sup>th</sup> that they finally started us down the path of a live donor process. In hindsight, this has to be one of the biggest, most maddening questions about this entire saga. We had



inquired from very early on, even when we were in San Diego about the live donor process. We wanted to get screened and ready just in case and we continued to be met with resistance to this process until Wyatt had deteriorated in what looked to us almost like mental retardation. We were very, very frightened during this period and we could sense that Wyatt was losing his battle.

But in many instances, the doctors still did not seem quite as cognizant of how far along he was in his sickness! They didn't start me in on the screening process until later in the day (so the

results didn't come back to us until mid-afternoon the next day) and we were told to only put out word to blood relatives at this point. We also do not fully understand why they had to wait for results on me before beginning with my wife... shouldn't they have worked us both up simultaneously to maximize time? The answer at this point was "no" and unfortunately, that precious one day lost proved dire in consequence.

After meeting a ton of resistance from the doctors on screening my wife for being a live donor (they believed she was too overweight and initially, felt she wouldn't be a good candidate for the surgery), we finally insisted heavily that they screen her anyway... what did they have to lose? We finally received some support from our liver coordinator who commented "lets do the CT scan first since it costs like six grand to do the blood work" (is cost an issue for some reason?). Finally, at about 8pm on Friday June 20<sup>th</sup>, we received word back on the results of the scan... she was a good match! We were floored and could not help but feel very mistrusting at this point for all the resistance we received to this whole process. We knew the clock was ticking and we could already feel that despite their best efforts to keep us out of the live donor process, this was the way they were going to have to go. In a sense, we were starting to feel that he was going to be near death by the time they wheeled him into the transplant room. We had brought this concern up to several people including Dr. Hong (the live donor surgeon), Dr. Mann (the hepatologist that interviewed Trisha and conveyed the team's reluctance to even consider her for a CT scan) and even some of our relatives who were shocked to hear that there was a possibility that he could not be saved if a donated liver was not ready in time.



## Transplant Scheduled

Finally, on the morning of Saturday, June 21<sup>st</sup>, we received some hopeful news (or was it again, another case of underestimation by the doctors in how sick he was)... Wyatt's transplant was scheduled for... Monday. In my blog the night before, I had predicted it would have to be right away on Saturday or Sunday, so this caught me a little by surprise..

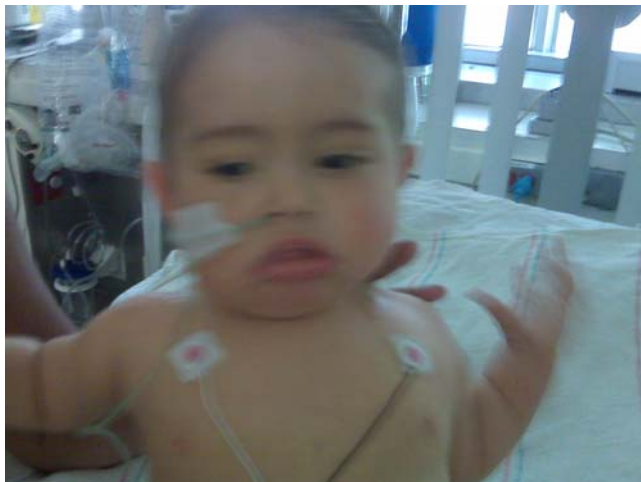
As I feared, when I arrived at the hospital on Saturday morning, I knew right away that there was no way we had enough time to transplant on Monday. Wyatt was in terrible condition and I began to feel a deep sense of dread for the weekend. His breathing was extremely labored, his agitation was active, but for the first time, really tempered because it was as if he had no energy. The nurse told me that she had insisted he needed to be intubated... a request that was initially rejected, but finally accepted and they moved forward with the intubation. Also at this time, the doctors gave me welcome news... they wanted to transplant using Wyatt's mother Trisha as a live donor on Sunday rather than Monday.



Between this news, and the decision to intubate Wyatt, I started to sense a sudden change in the wind with the doctors and staff. There was a very elevated sense of urgency. It wasn't that they weren't previously concerned or urgent about our son's health, but this was definitely the first time the entire week that these people seemed to be on the same page as us. Why that gap between us and our doctors hadn't closed sooner in the week, is a question we will never fully understand.

## A Frightening Moment

As I waited outside for Wyatt's intubation, I never could've imagined what would take place over the next hour or so. I walked back in after the procedure was complete to find Wyatt breathing with help from a tube. It is very difficult to describe the feelings that rush through you when you see your child this way.



And unfortunately, my somber feelings would soon turn to dread as I watched what was beginning to unfold right before my eyes.

From what I understand, it is standard procedure to take an MRI of a patient who is recently intubated. But as they worked on getting him prepped and moved over to the portable bed, something began to happen. The nurse suddenly became very determined and

focused. The help from the rest of the staff all began to closely monitor his numbers on the portable machine. The air was thick with tension. Something was wrong.

Wyatt's oxygen saturation levels were dropping and they didn't know why. They began fidgeting with the tube in his throat talking aloud about what could be going wrong. Several additional staff

members began circling his area and it wasn't long before he was being watched by a good half dozen staff members of the PICU, if not more. I just sat there, I felt the features of my face become that of someone who was in utter shock and horror. All the while, Wyatt, even though he was heavily sedated and continued to get a bunch of meds pumped into him in rapid succession, continued to move and jitter, almost as if he was trying to fight whatever it was that was bothering him.

It's very hard for me to know exactly how much time had passed. It felt like hours, but probably wasn't more than maybe a half an hour, maybe even less. There was something else... when they attempted to move him back to his bed, I remember seeing a moment where the staff held his body and lifted but his head was not supported. His head dropped quickly as it was very limp and heavy and I honestly don't remember if it had hit anything, but I do remember thinking "yikes, careful!" One of the nurses said something about it, but didn't seem all too concerned with the incident. But it definitely sticks out in my mind and little did I know that it would come full circle in the near future.

Finally, things began to calm down a bit. Wyatt was back in his bed (still not resting very peacefully, his hands and feet were continuing to move lightly yet sporadically). The doctors finally had a chance to tell me what was going on. Basically, for some reason he was now bleeding into his lungs. This is a problem for patients with acute liver failure because the liver controls clotting of the blood (among other things) and when the liver has failed far enough, internal bleeding can happen spontaneously or can even be caused by the slightest irritation.

But as my father walked in and we began discussions about dinner, I couldn't help but feel a nagging fear in the back of my mind that something major had just happened and the feeling that if he didn't transplant soon, we could possibly lose him continued to linger for the rest of the evening.

### **Transplant Time, But Who'll Donate?**

When I came back from dinner, I received some welcome news. They were exploring another liver! As it turns out, I was a bit skeptical we would get it (it was earmarked for another patient who was apparently in even more critical condition than Wyatt even though we recall being told previously that Wyatt would be the first patient in line for a new liver at that hospital), it was nice that we had some potential options. If Wyatt did receive that liver, then they would proceed with the transplant at midnight (what happened to Monday right?). If not, then Trisha was ready and willing to save her son's life by donating a piece of her own liver and that would take place at 9am.



Or would it?

As I received news later that night the other patient would indeed receive the current liver offer and begin surgery at midnight, I also found out that they were exploring two other offers for a cadaveric liver. They were looking into one and the second, while on paper it might've been a good fit, was on the east coast which proved a logistical problem. Therefore we were told by Trisha's surgery team that the plan was to move forward with her the next morning as the donor. Before I left the hospital around 10pm, I told the GI doctor on call and my nurse that night that I was bummed to hear about not getting the liver but that it was probably as it should be since we had Trisha lined up and the other patient urgently needed that one.

Later that night I was writing in my blog that I believed they would most likely transplant with one of the cadaver livers and not my wife when I received a text message from her telling me that very thing. The doctors were flying in the liver from the east coast to analyze it. They continued to move on getting her ready (by giving her an enema and drugs to clear out her GI tract) and didn't alert her of any changes, but I was almost certain they would not go through with it using her. I knew it because at every turn, these people did not want to do the live donor procedure... it was so blatantly obvious that it gives me the chills to think about it. I left the ICU around 10pm or so, as I left, I noticed a sign on my son's bed that read "If I am sleeping, please do not disturb me... Wyatt".

### Wyatt's Fateful Morning

Around 6am on Sunday, June 22<sup>nd</sup> (1 month to the day we were admitted into Rady's in San Diego), I received some extremely exciting news... the liver from the east coast was a fit (at least that's what they told us)! They would move forward with a transplant at 9am while Trisha was not going to be needed as a live donor.



Right around 8am, I was standing by in the PICU beaming from ear to ear. I was so happy that momentum had finally taken a turn for the better and that my son, who had endured a month of sickness, tests, needles, wires, drugs and doctors, was finally going to get his chance at a normal life... not a moment to soon! I happily reported to nurses and other staff members the great news and even shared some laughs with the GI doctor who admitted to me that morning that he and the nurse of the other liver transplant patient (the little girl) hadn't heard about the acceptance of the liver

for a good hour or two after I had told them. Ironically, my wife and I knew what was going to happen with that little girl for over an hour before her own parents and doctors would know.

But hey, we were all in good spirits and we joked how from now on, when they wanted updates on livers, they would just talk to me instead of the liver team.

It was right around this time that I heard my nurse mention one of his pupils being dilated. I didn't think much of it since we were only an hour away from transplant time and I felt that the finish line was nearing. Nonetheless, I did start to notice a few other doctors and/or nurses looking at Wyatt and heard them discussing taking him to get a CT scan on the way to the OR (operating room). I asked why and one of the nurses mentioned that it may be due to sedation or other minor issues. Nothing to be worried about. So I continued to walk around with a big smile on my face as they readied him for the CT scan and made arrangements with radiology and the OR team.

Then, everything changed.

Dr. Weiss examined Wyatt with his flashlight and right then and there, I saw in his face a deep, deep concern. He turned to me and very bluntly, almost quickly, told me some sobering, sobering news. One of Wyatt's eyes was completely dilated and neither of them were responsive. He told me that this usually leads to a neurological problem, often times a sign of major swelling of the brain. If so, this would keep him from transplant. I asked him, "ok, then how do you treat the swelling to get him ready for the transplant?" He replied, "Well, we can't... usually, it's fatal."

My heart literally fell into my stomach and I once again felt the features of my face distort into utter terror. It really was the way he said it that hit me like a ton of bricks. This wasn't a "possibility". This was a "likely". Immediately I began to sob. I look back on this now and a huge question mark remains on this particular finding... why wasn't there any concern sooner? Why was this the first we'd heard of this problem with his pupils and a potential swelling of the brain? Had the nurse not checked him all night long (by shining the flashlight into his eyes), perhaps because of the "do not disturb" sign?

As Wyatt's father, having gone through this with him over the past four weeks, and knowing that we were literally on the way to transplant within minutes, I had a dizzying cocktail of emotions run through me that ranged from fright, sadness, denial and hope... all wrapped up in a ball of wax sitting in the well of my stomach. I grabbed a box of Kleenex, called my wife and told her the terrible news. She came down immediately even though she was still extremely nauseous due to the medication she had received all night long. I can't imagine how it felt for her to hear my sobbing voice telling her that it was very possible that Wyatt had suffered some sort of fatal injury to his brain.

### **The Realization**

The moment you realize that your child is dead is a moment words can never fully describe. All I can say is, my world literally crashed all around me and my wife and I ended up on the floor sobbing and crying out uncontrollably. I will never forget the shouts of "Why" and "No" coming from the lips of my wife as we let out our screeches of horror and cried buckets and buckets of tears.

The CT scan had come back showing massive swelling and edema of the brain. In addition, there was hernia that essentially caused his brain to slip downward on his brain stem. They arrived at this conclusion as we sat in the hallway of the OR, debating on whether or not they were going to transplant. Ironically, at first, they had every intention of moving forward with the transplant. At this very critical point in time, no one knew for fact that my son was brain dead and had probably been



so for at the very least a couple hours, but more likely, for about 10 to 12 (according to a potential timeline proposed to us after the fact over the phone by Dr. McDarmid). 10 to 12 hours... right around the amount of time that had passed from intubation and the events that happened afterward (including the moment where his head snapped back, something Dr. McDarmid in our phone call the next day would admit could've caused the swelling in his brain). As I look back at this moment, it becomes crystal clear that there was a huge, systematic fuck up on the part of this team and/or this process. For instance, if the cadaveric donor hadn't come in, they typically start the live donor about 1 hour before the patient. My wife, who was originally going to be the donor before this east coast liver rolled in at the last minute, could've been under the knife, her own life in jeopardy, the very moment that they determined my son was brain dead and could not take a liver transplant.

Another revealing piece of information came out during these moments. We were told for the very first time that the cadaveric liver they were considering to transplant at this time was an A blood type versus an O blood type for Wyatt. We were told specifically from day one that the liver blood type had to match the patient blood type and then it was revealed about 2 days before this

took place that only in the rarest of circumstances do they attempt to do the cross type transplant. Had we known, we never would've approved a type A liver for my son over my wife as a donor... this was a type 2, autoimmune hepatitis that would already likely be very difficult to treat after a successful surgery. To add those additional complications from a type A liver to this scenario, seems utterly ludicrous.

But we didn't have an option to be choosy at this moment and they were going to move forward regardless. An anesthesiologist came by, asked for a signature to consent to the procedure (something I had completed the day before), told us he would take good care of our son, and asked us to wait in the waiting room. We kissed our son good-bye and began to head out of the corridor, crying, frightened, but with a glimmer of hope that the transplant could turn the neurological problems around.

Unfortunately, that was not the case and we were told to wait and come back as we were about to move through the doorway.

At this point during these events, my mother, mother-in-law and sister-in-law were all present. The three of them along with my wife stayed back waiting for what was going on while I stayed fairly close to the doctors to try and catch as much information possible. They called down the neurologists (curiously, people I had never met before in the two weeks we were there) and one of them, seemed very agitated. He had a thick beard and a huge growth on his tongue that caused him to talk with a major lisp. I read his body language like a book and I will never forget two phrases he said in about the 5 to 10 minutes he stood there talking with PICU doctors, transplant surgeons and the nurses... "How long has he been like this?" and "I don't know what to tell you!". My impression of this guy was that he was very pissed off because he knew that they had called him down to look at a brain dead infant with his devastated family looking on. I went over to my family and told them he was gone but my mother told me not to lose hope. Unfortunately, I knew it was too late, there was no hope left to lose. At this point, the debate on whether they should even move forward with the transplant had ended.

The PICU doctor came over to me and explained that he had experienced a fatal swelling of the brain and that they could not move forward. They were going to return him to the PICU where we were to meet with the team in a conference room to talk about next steps.

## Saying Good Bye to my Son

About 30 minutes later, we were sitting with a handful of doctors who expressed their heartfelt sympathies and apologized for this turn of events as we sat there sobbing and blowing our noses, shock completely taking over. They didn't tell us much about the technical terms of his death and



even if they had, we probably wouldn't have been able to process it at that time. They gave us our options and told us Wyatt had absolutely zero chance of ever coming back. We didn't have a choice but to ask them to remove him from their machines and let him die in peace without pain and in our loving arms.

As I went down to inform my devastated family that he was gone and they were welcome to come say good bye to our little "Pie Man", my little boy died at 11:19am in the loving arms of his mother who felt his heart and breathing stop against her chest. For the next hour, she simply clutched his limp, yellow body tightly as my family members came through crying rivers of pain and sorrow, saying our good byes and embracing each other in sobbing disbelief.

I will never forget the feeling of my son in my arms as he took his final, machine-driven breaths. Tears dripping all over him, my wife and I stroked his soft hair over and over wondering how this possibly could've happened. We were transferred to UCLA

Medical Center to save his life and instead, here we were two weeks later holding his limp body in our arms... the beautiful light in his eyes and his smile replaced with emptiness and a sad stillness.

We kissed him over and over, stroking his head, chest, arms, legs, hands and feet and told him how sorry we were. How sorry that he didn't get his chance at life... how sorry that his final few weeks were filled with needles, wires, pain and sickness... how sorry that we were unable to protect him from the rocky path that led us to this point... and we told him how much we loved and missed him and that he would never ever be forgotten.

## An Aftermath Filled with So Many Questions

So how does an infant fight liver disease for week after week with such strength and heart yet end up brain dead on the way to a life saving liver transplant? This is the question that we probably will never have answered. Wyatt and our family will forever have to wonder “what if” and while UCLA Medical Center gets its new building and another crack at Newsweek’s Best Hospital for ‘08, we will be burying him in San Diego



I promised my little boy that he would not die in vain... that his story will affect change and help people in the future. That is my pledge to him and the rest of his family. But so much uncertainty lingers and I hope that one day, we can get real answers to these and other questions...

1. Why was there such a discrepancy between how the doctors at Rady's felt versus how the doctors at UCLA felt regarding him being ready to transplant and why couldn't he have been listed "Status 1A" while undergoing treatment?
2. Why was there a continued pattern of misunderstanding for how sick Wyatt was when Rady's and my wife and I continued to express our concerns as the UCLA doctors continued to push out the transplant ultimately leading us to simply run out of time?
3. Why was there very little information given to us regarding what to look for in neurological issues and further, why wasn't anyone from neurology involved in the continued care of our son if this was a potential outcome of this disease?
4. Why would the doctors even remotely consider transplanting an autoimmune liver patient with an incompatible blood type donor instead of a compatible live donor and why wasn't the live donor option scheduled sooner (like Saturday morning, my wife was ready)?
5. Why was the neurologist with the lisp so agitated by the situation and why was a doctor (whom I believe to be Dr. Farmer the head transplant surgeon) seen throwing his apron in disgust in the hallway near the PICU around the same time we were down in the hallway learning of our son's passing (as seen by my Uncle)?
6. Why weren't we and anyone else who was willing to be worked up as a live donor, if not immediately, at least at the first hint of the failed steroid treatment and/or the first hit and miss from the cadaveric donor?
7. What exactly happened during the full day of negotiations between Rady's and my insurance company regarding the transfer to UCLA and if an insurance company can dictate that type of major upheaval in care, why are there no protocols or standards in place to make sure that the previous treatments and care are not lost?
8. And most of all, how does a sick baby fight for an entire month needing a liver transplant only to be confirmed brain dead in the OR minutes before the procedure... how could they not have known sooner about the neurological danger he was in?

## **Finding the Truth**

Obviously, we have our own thoughts, ideas and theories on the answers to the above questions. Outside of the care we received at Rady's Childrens Hospital in San Diego, we believe we were cheated out of at the very least, a chance for transplant for Wyatt and at the most, a life full of medicine and continued care, but one that he would still be living, surrounded by the family that loves him so dearly.

Instead, we continue to search for the truth... a quest that will likely end without satisfactory answers and with only the loving memory of our beautiful son to try and fill the empty void left from this tragic story.



**Wyatt Reese Leamon, aka "Pie Man"**

Born: 9/2/07

Admitted to Rady's Childrens Hospital: 5/22/08

Died outside the OR on the way to a transplant at UCLA Medical Center: 6/22/08