

# Beautiful Crisis: The Blog

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Here, you will find the original 22 blog entries I posted during my experience in the Burn Unit, through the birth of my "Miracle Baby" and one month into our journey of recovery.

I have transferred the entries here in their original state because somewhere in the world there is a mother in a burn unit...or seeing her child through an accidental injury who needs to know she is not alone. Maybe my words, this experience I lived that is now a story I tell will bring her comfort.

I've also included 8 more entries I wrote in the aftermath, which reveal a beautiful ending to the story I started to tell the night my toddler son was injured....these allude to the continued adversity I faced through intense postpartum anxiety heightened by trauma, repeated surgeries, burn injury care, the tears of guilt I cried and a complicated pregnancy loss...

I found my way back to WHOLE with resilience, strength and a renewed sense of hope because I continually chose things like optimism and gratitude. You'll find what's positive throughout these entries that capture the moments of humor, love and joy I experienced in the most difficult experience of my life.

### **How we got here...**

April 6, 2013

While many of you by this point are familiar with the situation, here is the story of how we got to where we are....

Pregnant with my third child due April 25th, I have had a relatively good pregnancy except that our little guy, who we plan to name Henry, is suspected of having a condition called Posterior Urethral Valve (PUV). Basically PUV is a blockage in the urinary tract that causes fluid to build up in his bladder and ureters causing them to dilate and then eventually this fluid or "reflux" can make its way into the kidneys. While the enlarged ureters are not good, the major concern begins when the kidneys start to take on fluid as this causes kidney damage that in some cases is not correctable leading to dialysis and an eventual kidney transplant.

When this condition was first caught at 21 weeks, due to the enlarged ureters, I was told that it is frequently seen in boys and Henry would likely outgrow it by the time he is born. I was monitored almost weekly, but around 27 weeks, I was told the ureters were significantly worse and sent to a more in depth sonogram that confirmed there is indeed a blockage somewhere causing the reflux, dilation and potential kidney damage. After consulting with a pediatric urologist, we were told that while things could change by the time he is born and they get a clearer picture of what is going on, surgery by 3 days old to clear the blockage was nearly unavoidable. The thought of a newborn undergoing general anesthesia and a surgery is a lot to swallow, but if the condition is what they are almost certain it is, the longer the surgery waits, the further the damage to the ureters and kidneys. However, anesthesia risks aside and with minimal kidney damage this would be a relatively low risk surgery, reverse the kidney damage, and baby Henry would be perfectly normal and just need lots of follow-up visits at the urologist. Still, I was warned that if things progressed and either the kidney damage in utero was severe or there was a drastic loss of amniotic fluid, there would be an intervention and the baby would be taken early to temporarily alleviate the pressure until he would be old enough to endure the necessary corrective surgery.

Given that at all of my scans I had plenty of amniotic fluid, and the ureter size was pretty much the same, we simply continued to monitor the situation to see how it progressed. While I was concerned, I was hopeful that I would carry to term and while they were saying a surgery was "highly likely," was realistically optimistic that he could still grow out of this and it would be just another one of those "pregnancy scares."

By around 33 weeks I started having very frequent and strong Braxton Hicks contractions and so I was advised to take it easy. Well, with a 2 and 4 year old and a household to manage, that is a difficult order to follow but my doctor wanted me to at least make it to 36 weeks so that the baby would be strong enough for the potential surgery.

At my 36 week scan, I was relieved that I had made it until Henry was nearly "full term" and expecting the same news I always got: things aren't any better but they aren't worse. I always considered this good news. Instead, I was told that both ureters were significantly more dilated and one of the kidneys was beginning to take on fluid. After each sonogram and consult with my OB, I would call my pediatric urologist to give him results and with the fluid in the kidneys he expressed concern and asked that I come by with the sonogram photos to see if an intervention was necessary.



This appointment was the next evening on Wednesday, March 27th. As I was walking out the door with Eddie to make the appointment, I heard my babysitter scream and when I turned around, saw her running to the sink with William. A pot of near boiling water had spilled on him and all I remember is ripping off his bicycle helmet and shirt, handing him to Eddie and before I knew it, was running through the doors of the emergency room at North Shore Manhasset screaming for help.

We were eventually transferred that night to Nassau University Medical Center as they have the best burn center on Long Island. William had 2nd degree burns on 16 percent of his body covering his face, neck, chest and arms. By Thursday morning, he was in the operating room undergoing a procedure called Oasis where a product developed from the lining of pig intestines is applied to the burns as it has regenerative properties similar to those of skin cells. This layer is covered by an antimicrobial layer of silver to prevent infection and then a bit of gauze to hold everything in place.



Most of the Oasis treatment took well, but there were areas of concern the doctors said were likely to need another procedure. After 6 nights in the hospital, we were discharged with the hopes that William would heal better at home. Indeed, in the past week he has regained his appetite, much of his personality and is walking around and playing with his brand new bicycle even though he still does not have full mobility in his neck and arms.

While we were hopeful before yesterday's follow-up with the doctors that even William's deepest burns would simply continue to heal, it is apparent he will need a skin graft surgery. The doctors are waiting until Monday to schedule the surgery to see if this area shrinks down in size so the graft can be done on as small an area as possible. On Tuesday, I go to my OB to reevaluate Henry's situation: stay pregnant or intervene. As you can see, we are not completely certain how things will fall into place: Will we be able to address all of William's needs before Henry either decides to come or needs to



come? Will the situations overlap? Will I have Henry first and then see William through the second surgery?

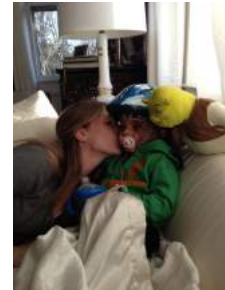
The night of William's accident, I was completely overwhelmed with the thought that I could have both of my boys in different hospitals at the same time. Luckily, my labor never kicked in with all of the stress from William's situation and my OB and pediatric urologist decided that Henry could stay put where he is for at least another week. I am hopeful that because of all of the prayers, love and support we have received from friends and family, the care and compassion of incredible nurses, the expertise and understanding of all the doctors, and maybe just a little bit of luck...we will continue on this path to have the best possible outcome: Henry will safely remain in my womb until I can see William through all of this. As I compose this story at 37 weeks and 3 days I realize time is of the essence but I am praying that Henry can sustain a little while longer and can come as his brother and sister did at around 42 weeks.

While I don't know what the journey ahead will bring, for the moment I am still pregnant and feeling well all things considered. William had a good day - he is eating, happy, active and at the moment napping peacefully. Catherine is happily playing with her Grammy and Eddie is getting his first and very well deserved break from this all. The weather is shifting - it feels like spring is finally here and while I never imagined this situation is what the spring of 2013 would bring, I also never realized how many loving and supportive people I had in my life. Wait...let me rephrase that...I have always been surrounded by amazing friends and family, but maybe I never realized the lengths they would go to support my family and me when we needed it the most. For this, I am blessed and can focus on something very positive in the current situation.

### **William's Update**

April 8, 2013

As expected, William will need skin grafts for areas on his left shoulder, chest and right arm. Since today's visit was 11 days from the initial burn, the areas being watched aren't anticipated to shrink much more so it is best to go ahead with this surgery. We will admit at the hospital on Wednesday, and his surgery will be at some point on Thursday. We will likely be at the hospital recovering through the weekend.



While I certainly am not looking forward to repeating the process of holding William as they put him under, seeing him in pain after the surgery and the regression in his behavior that will follow, I am somewhat relieved that the surgery will be done so that he can truly begin his healing process. He hasn't slept more than 3 or 4 hours at a time since this all happened due to the discomfort of the deeper burns...and the doctor's visits are always difficult as they pick, poke and prod at his bandages, which is very painful. While there will be initial pain after the graft, the burn pain should subside after the new skin is in place and from what I have been told time and time again, children heal miraculously well so this all should be over for him soon.

Tomorrow I have my OB appointment to see what is going on with Henry, but I am hopeful that I will

be granted just one more week! That is really all I need to see William through the hardest part of this mess. I am optimistic but keep the prayers coming.

For now, we are cherishing the time we have at home...play, laughter and nourishment are our three priorities. William's new red bicycle is his current obsession and because of this, I have broken my "no outside toys in the house" rule and he rides it in circles through the house while the movie Shrek plays on repeat (as it has been for the past 11 days...but who's counting). His new favorite line after I tell him that I love him is, "thank you sooo much." Little stinker.



Catherine is doing very well considering all of the changes of late and handling the news that William and Mommy are going back to the hospital again like a champ. She is one tough cookie, my little girl.

As for me...I am holding things together as best as I can...trying to stay focused on the present otherwise I get totally overwhelmed. Everyone is commenting that I am so strong and poised but trust me, I have my meltdown moments as I am just downright exhausted and let's face it....at 9 months pregnant...a hormonal mess! I am just coping and putting one foot in front of the other as any mother would.

Thanks for your prayers, encouragement and support. I'll be back with Henry's update tomorrow.

### **Henry's Update**

April 9, 2013

I cannot convey how relieved I am to report that Henry's condition is no worse than it was last week so it looks as though my prayers have been answered for time and I will be able to see William through the surgery and hopefully his transition home.

Further, my amniotic fluid is "fantastic" which means that while things are not functioning as they should in Henry's system....it is still "working" quite well considering the obstructions so I think that while the surgery is necessary, I am not as worried about the kidney damage as I initially was. Thanks to all of the meals from our family and my incredible girlfriends I regained the weight I had lost during William's hospital stay and there are no apparent signs of labor so I am not worried about anything spontaneous happening during the next 5 days at the hospital for William's surgery.



For now, we are enjoying our last night at home before we are back at Nassau University Medical Center in the Burn Unit tomorrow. I will continue to keep everyone posted when I know more details about William's surgery, etc. but at least we know Henry is right where he needs to be for at least another week!

### **Change...the only constant in life...**

April 10, 2013

This morning we packed up, took William to breakfast and arrived at the hospital by 11 am. With our bags and a cranky William in tow saying, "I don't want to go here I want to go home," the head nurse with greeted us, "It's nice to see you but why are you here? You should have been called and told your surgery was pushed to Friday."



Let's just say that with a simple glance, the nurse scurried off and the resident doctor arrived faster than he ever has and had to explain to a very frustrated, 13 night sleep deprived and hormonal 9 months pregnant woman who's 2 year old is going through a very painful and difficult time why a simple phone call wasn't made to let us know the surgery had changed. I might have made this more intimidating than his first time in the operating room but he handled himself quite well and my labor didn't kick in.

Turns out there is no explanation for the lack of communication. They totally messed up. Yes, the poor little guy had to go through another dressing change...and it is hard to have to go home and endure another sleepless night and then face the emotional process of trekking back to the hospital tomorrow but the good in all of this is that apparently the head doctor at the hospital has "taken a special interest in Williams's case" and is insisting on doing the second surgery and can only operate on Friday.

While the doctor initially slated to do the surgery has an excellent reputation, if we need to wait just one more day to have a doctor who has been practicing longer and is respected even greater, then we wait a day and have the best possible surgeon operate on William. We've come this far...

While William has great days, nights are rough with him as some of the nerve endings are starting to grow back and so his pain has increased. It is hard to keep him comfortable but it's just two more nights and then the grafts will help with this. Please keep praying for his next two days to be as pain free as possible and for his surgery to go well on Friday. I'll be back tomorrow to confirm that things are still playing out according to plan.....

Xoxo

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### **Moving Forward...**

April 11, 2013

We are checked in and are through all of the poking and prodding for today. William is happy considering he knows where he is. The nurses and doctors are all excited to see him with a personality....he didn't have much of one the last time we were here. He has been spoiled by his favorite nurse Pat with cookies and a donut....and she even figured Mom needed a break from Shrek and it looks like her suggestion of The Wiggles will be on replay for the rest of the night. At least William is happy but I told her if he is still watching it during her next shift I am wheeling the TV and our bed next to the nursing station so she can enjoy The Wiggles with me!



So all things considered we are in good spirits and settled in. His surgery is slated for first thing tomorrow morning.

Until then....it's a wiggly party....

### **Out of Surgery and Resting**

April 12, 2013

We made it through the surgery and while it was longer and more involved than the doctors initially thought, William is stable and resting and should heal well. I will be back with more details tonight or tomorrow. Thanks for all of your thoughts and prayers. Xoxo

### **My Strong, Resilient Little Boy**

April 13, 2013

If there is one thing I have learned about burns, it is that they evolve from the moment they happen and are difficult to predict. When we first were in the ER there was concern that some of the deep second degree burns on William's neck, chest and right arm would evolve to an even deeper burn, but the doctors were optimistic that the Oasis treatment they did the following day would allow some of these areas to shrink and possibly heal.

At the follow up visits, the doctors were pleased with the take of the Oasis...on his face, chin, most of his arms and lower chest the treatment was peeling away and revealing areas of brand new pink skin. While the doctors knew areas on his chest and right arm would need grafting they were insistent this area was becoming smaller and smaller as we waited the two weeks from the initial burn.

On Thursday we checked in and did all of our pre-op stuff. This included a very difficult blood draw that the resident doctor came to do himself. While I had been insisting something was up with a putrid odor from William's wounds and extreme discomfort leading to sleepless nights for a week, it wasn't until he was in close proximity to Williams wounds that he realized the extent of the smell was more than just an overly scent sensitive pregnant woman's complaint.

While I was told there would be no dressing changes until William was sedated in the OR the night nurse came in with orders for one due to the strong odor. While these are always hard I didn't think much of it as I assumed we were just removing the outer layer of gauze. As we started removing the dressing more and more layers of the treatment and gauze were falling off and I was soon staring at his chest, as open raw and exposed, as it was the night of the burn. While I am no burn specialist, I have researched enough to know at that point that his whole chest would need a graft. Though extremely painful, the wound clean allowed William the best night of sleep he has had since this whole ordeal began but I was up dreading the surgery as I knew it would be longer and more involved than we were led to believe as I had just seen a very large third degree burn.

They came for William at 6:30am and by 8:15am they sedated him in my arms





and I placed him on the stretcher to be taken in for surgery prep and the general anesthesia. We were told the surgery would be two hours but mid way a nurse came out and said they were only 2/3 done. At this point they had harvested skin from one side of his butt to be stretched to cover his whole chest and they were next taking skin from the other side for his right bicep and forearm.

The surgery was four hours long in which they grafted 11 percent of his body. The Oasis only saved 5 percent from grafting. Due to the more extensive skin harvesting there was a concern about blood loss and while there was discussion of a transfusion it didn't happen yesterday and I am hopeful that it won't be necessary.

Seeing him so raw and beat up in recovery after that horrible dressing change and four hours of stressful anticipation was my lowest point so far. However, by the time we were back up in our room, William was asking for Shrek and ordering me to snuggle. Within an hour he was drinking his "seltzer" and ate 4 chocolate munchkins. He then slept relatively peacefully through the night with little medication.

He was in a bit of discomfort this morning but after some Motrin was able to laugh at Shrek with me and at Dad's silly jokes and now is napping. They will do another blood draw today to see if he still needs the transfusion but he looks pretty good to me so I don't think it is necessary.



Because grafts are sensitive to infection and he has open wounds now on his butt we aren't taking any visitors in fear of infection. This could prevent the grafts from taking and mean another surgery and I think we have endured all we can take. I am not taking any chances until the doctors look at the grafts either Sunday or Monday.

Initially we were slated to go home on Monday but with the size of the graft anticipate Tuesday is the earliest we will discharge. Until then, we have Shrek and The Wiggles (though thank goodness he only wants this every now and then because the song "fruit salad yummy yummy" is just torture). We assume the "snuggle" position except for the negotiated bathroom break and there is a rotation of amazing nurses who know us very well and go out of their way to take care of William and Mom...they have really helped me through this ordeal. Most of all my little guy has a very strong and resilient spirit so I know he will pull through and heal. For a week at home he was bouncing around and riding his bicycle with a very painful open wound on his chest. While his poor little tush will be raw now too, his chest will finally heal. This hopefully is the road to recovery and I am certain he will want to be back on that bicycle as soon as he can.

As I first noted, burns are very unpredictable so the doctors are giving us no promises about recovery. But this Mom is pulling and praying that this is the beginning of the end and soon this will just be a time in our lives we look back on as our most difficult hurdle and one that made us all stronger and closer as a family.

### **Doctors vs Mothers and Nurses**

April 14, 2013

The doctors here, God Bless them, are nothing short of amazing. They are skilled and knowledgeable



and without a doubt, good at what they do. We have a team of three doctors working with us...and each of them have good bedside manner, attentive listening ears and are responsive to any questions we have whenever we have them. However....they do what they need to on the surgical end and then go about their next case while we are left to manage the aftermath with the care of the nurses. This is how it all works...I get that...but now I am going on three weeks of tolerating it.

Since William has grafts on his chest, left shoulder, right bicep and fore arm, mobility in his upper body is restricted. He can use his left arm from the elbow down and is able to reach just enough to get a munchkin in his mouth or hold a drink. His right arm is in a cast to keep it in the L shape position and is wrapped all the way down to his fingers so while he can't bend this arm or move his hand, he can raise it up and down. There is a patch on his neck that was deep but not grafted so he doesn't have much side-to-side mobility. This is pretty much what he has been managing with for the past two and a half weeks...only now, hopefully the skin underneath the bandages is finally healing.

Couple this with a brand new wound on his poor little butt where they grafted. Skin was taken from his entire right cheek and most of the left....at a superficial thickness...but just enough so it feels like he was burned there too. The way this heals is by drying and scabbing so doctor's orders for yesterday was that the dressings on those were to come off and it was to air dry. Yes, this is very painful. Typically this means kids lay on their stomachs but given William's grafts this position isn't possible.

Dilemma, right? Our day nurse, Pat, got us through the removal of the dressing on one side and at the doctor's suggestion that we use a blower to help speed up the drying, she replied, "I think we should skin your butt and then put a blower on it." Still, desperate to get this guy on the mend, we were willing to give it a try so Eddie held a blower to Williams's butt for as long as he could tolerate it. A few hours later, we exposed the second cheek and while he refused the blower (wouldn't you) he rolled over toward me far enough onto his right shoulder that he was able to air most of it. After over 8 hours in this position his face and arms started to swell so much that his eyes were closing and by the time the night nurse Rhonda was on, I was holding William in my lap with his tush hanging between my legs. This lasted about an hour and helped his swelling so Rhonda told the doctor we needed another solution and so they put some drying silver stuff on and then a diaper and he was finally able to lay somewhat on his back and we got a decent night's sleep.

Thank goodness for peaceful rest because the doctor's orders for today were that he get out of bed to walk around and play. He was resistant at first but eventually we got him to the playroom and before we knew it, he was slowly walking around, giving high fives and allowed Mom enough time off snuggle duty for a shower. He even requested his Thomas boots which paired amazingly with his hospital gown and diaper and with Eddie in his 90s wardrobe that he discovered yesterday at his parents during a quick shower break, I haven't decided who made more of a fashion statement.



Throughout this ordeal I have realized that while doctor's orders always have the best of intentions they aren't always the best at the moment. Sometimes it takes a little compromise and sometimes Mom really does know best. The last time we were here I was insisting most of his pain was from a catheter (that was done incorrectly twice, then put in a third time) so when something still seemed off after its removal I insisted that he was tested for a UTI and while they only did it to keep me

quiet...shocker....he had one and the minute an antibiotic was started his pain subsided. For a week I was complaining about the seeping wounds and terrible smell and then a major dressing change is done 8 hours before a surgery when the pain could have been spared for the inevitable anesthesia in the OR. Really? And now you want me to let this kid's butt dry out naturally? Do you happen to have any suggestions for this given his chest wounds and lack of mobility?

Needless to say I wouldn't have remained as patient and collected without the nurses backing me up and really looking at what is best for more than just Williams's wounds to heal....they advocate for his comfort and spirit. This compassion and holistic approach to medicine is what has helped me through the many helpless moments where there is nothing I can do to comfort my child in pain but "snuggle" and tell him it will get better soon.



With this morning's activity and the nice nap he is now taking flat on his back (thanks to Rhonda's silver drying solution) I am hoping that these painful moments really are going away soon for William. He is certainly tolerating this all much better than I would if I were him. Such is the spirit of a child....and the reason I will fight even harder for his needs as his mother....

### **I can kiss both cheeks!**

April 15, 2013

No...not his butt if that is what you were thinking. ;) I think we need at least two weeks for that to heal...but today they took the rest of the treatment off the left side of his face and I cannot tell you how happy I am to see his whole face! It's a little red and rough and will be this way for quite a while, but will heal and eventually show no sign of the burns. As I type this, William is watching Shrek and constantly touching his face saying, "awww! better!" I am also allowed to "kiss the all better face."



The other good thing that happened today is when the dressings were removed, the doctors said the grafts look good and they are quite confident that they have taken. While they need to take another look tomorrow, they are anticipating we can go home on Wednesday. William still has a long road of recovery ahead but we are hopeful he finally has the hardest part behind him.

And for now, I am signing off because I am getting a request to go to the playroom...and then we are expecting Catherine and Daddy for dinner :)

### **A refrigerator meltdown and we are going home!**

April 16, 2013

Last night, William was the happiest he has been since this all began when he



got a visit for dinner from his big sister. He was holding her hand, walking her around and making her feed him pasta and chicken. It was so nice to feel like a family again, together even if only for an hour or two.

This morning I knew that the entire team of doctors would be in for "rounds" where they all look at the grafts together and make a collective decision on how to proceed. William had a mini version of this yesterday and while he bounced right back afterwards, today was a bit harder as he knew what was coming when he was taken away from Mommy and stripped down and about 10 strangers in masks came in to stare, poke and prod.

Afterwards he asked me to take him to the playroom and when we were alone, he put his head down in my lap and said, "Mommy I did so good. I'm awl done. Snuggle me." Poor kid.



Then, I was informed that the team decided it was best to keep him at the hospital until at least Thursday as they wanted to monitor him and do the dressing changes. They also wanted him to be walking around without a diaper on and trying that annoying blower when he was laying down so that his butt dried better.

All of this and I needed to leave in 15 minutes for my OB appointment. While Eddie arrived in time for a munchkin and bagel distraction, William knew I was up to something and was refusing to even let me put my hair in a ponytail so Eddie worked his Daddy magic and I was able to sneak off and at least change my clothes and brush my teeth.

As I went back to the room and passed the hospital bed where I have slept quite uncomfortably with William for two out of the past three weeks, turned off the TV that has no remote playing Shrek or The Wiggles on rotation (I am sorry but no remote, a kid who wants to watch the Shrek dragon scene and then the Wiggles fruit salad scene intermittently over and over again and my heavy 9 months pregnant belly that dreads getting up to make the switch are not a fun combo) then entered the bathroom with an automatic half sink that splashes all over the place, a stained floor, hand held shower, no shelf for even a toothbrush, sandpaper like towels that don't even make it around half my belly when I do shower and toilet that automatically flushes every time you move and just broke down and started to cry because again, my expectations were one thing and yet again I was being told this was dragging on even longer. After all the changes and roller coaster of events the past three weeks I just couldn't bear another setback even if it was merely a precautionary extra night in the hospital.

I had my pity party while soothed by the fluorescent lights, grey stained tiles, and flushing toilet of the hospital bathroom. When I pulled it together, I went to say goodbye to William in the playroom where Eddie informed me that the head nurse said I needed to throw out my food in the communal mini fridge as it was taking up too much room. At this point I marched....well waddled over to the nurses break room, interrupted a meeting and relayed that if there is a problem with my food in the fridge that feeds my kid who hasn't touched the disgusting mush dietary calls food at this hospital then they can accommodate me as they do patients with dietary or religious needs and wheel a mini fridge into my room. They can also replace the box of squeeze yogurts someone took the last time we were here...then the only food William would touch. If I needed to develop an allergy or convert religion during my doctor's visit I could make it happen so an order would be written for this.

And off to my OB appointment I went where I was told that things are again no better but no worse for Henry than last week so they won't induce. However, I am a ticking time bomb and at 39 weeks tomorrow there are some signs of a pending labor....very strong contractions among them. While I could very well still be waddling around next week, there is just no certainty and with a third baby....Henry will likely make his entrance sooner rather than later.

Getting some fresh air, a few good sono photos of Henry, good news that there is still no induction and an hour of girl talk with my best friend gave me enough strength to walk back into the hospital and suck it up for another two nights.

While I was hoping for a personal mini fridge and some magnets to hang my new sonogram photos, I was instead told that they were working on setting us up with a visiting nurse service so we could discharge. Apparently while the lead doctor thought it was best to keep William just to be super cautious as to not give us any setbacks, the other two doctors and nurses decided we had really had all we could bear and that William needed to transition back home before the baby arrives. I think this immediate change in plans had something to do with the fact that in the past three weeks the only meltdown they have seen me have (well besides the rant over the surgery miscommunication) was over a refrigerator.

So there you have it...a refrigerator meltdown and we are finally going home. While I had thought it would be tomorrow, Nurse Dorothy (who by the way solved our "no diaper" order by cutting a hole in the butt area so William didn't have to wander around completely exposed to air out) worked her magic and got us pushed out of there immediately. A mother of two....she gets it. Again, thank goodness for nurses and mothers!!!

As I write this, we are in the car on the way home. We will have a family dinner and celebrate with a cake. We have a visiting nurse starting tomorrow and the doctors promise me we are through the worst and while there is a lot of care and follow up needed it will only get easier with each passing day.



Phew! So it is official....Henry has stayed put long enough to make it through Williams's three week journey in and out of the hospital when he needed me the most. Now we can transition back home to as normal an existence as possible and catch our breath before the next hospital stay. Our prayers....your prayers for us have been answered. Thank you all...thank God! Somehow it is all looking up from here. After surviving the past three weeks, I know that we can make it through whatever we are facing with Henry. God will pull us through it.

### **There's no place like home!**

April 17, 2013

Everyone is much happier now that we are home and together as a family again knowing that the worst of it all is behind us. While our routine isn't what it was, we are trying as much as possible to reclaim it. For example, bath time in my house begins with 15 minutes of naked monkeys running around and while William cannot take his bath with Catherine yet, he was excited to run around with her in his bandages and cut out diaper. Their laughter and giggling was even better than I



remembered after a three week sojourn...it's the little moments as a parent that I find so heartwarming. It was also quite interesting having to explain why William now has ouchies on his butt and needs a hole in his diaper to help them heal to a very inquisitive 4 year old. I don't think I did much better than when she asked Eddie how the baby was going to get out of my belly and he replied, "uh between Mommy's legs" to which she concluded, "wow that must really hurt." That was pretty much her reaction about this too...she sure is gaining perspective this year!

William in general is doing even better at home now than he was after the first surgery. I take this as a sign of healing which is such a relief. His appetite is very good and he keeps telling me. "I'm home!" And I am ecstatic to able to reply with "yes, you are home and you are staying home."



Still, he needs to go through a daily dressing change, which is what the visiting nurse comes for. While I am able to make sure he has pain medication for this, it is a crummy experience for all as in order to get the dressings off they need water and the process of wetting his chest evokes screams that remind me of when initial burn happened. I think that he is experiencing trauma brought on by the sensation of water that reminds him of the actual event rather than pain from the dressing change itself. Unfortunately, we have no



choice but to keep doing them so I am hoping that what happens to be "exposure" therapy will eventually help him heal. I sure hope it gets better as while we have a nurse at this point he only wants me to touch him so I ended up doing everything today with the nurse assisting me. I can navigate this but afterwards was as worn out as William and more than happy to have a snuggle nap session to recover with him.

All in all I will take the good with the bad as we are home. William and I both slept sideways, upside down and backwards last night as we had this newfound luxury called a queen sized bed to snuggle in! Right now we are watching Bubble Guppies....how nice it is to have a break from Shrek....this too is a sign that things are looking up :)

**It doesn't take away his pain but sure makes me feel better....**

April 18, 2013

To Whom It May Concern:

On 3/27/13 my 2 year old son, William Assad, was treated in the Emergency Room at North Shore University Hospital at Manhasset. He suffered second and third degree burns on 16 percent of his body covering his face, neck, chest and bilateral arms. Among the procedures performed were a foley catheter. This procedure was necessary given the severity of his burns, but it is a very uncomfortable and invasive procedure for a young child already in pain even when performed perfectly. The first time it was done improperly. Then it was taken out and reinserted. While the nurse or doctor who performed this procedure noted there was no fluid coming out as it should have been, they were convinced it had been done correctly. Still, I noticed my son's continued discomfort from this area as its location was obviously separate from the pain involving the burns to his upper body. The pain from his groin area seemed significantly worse than that of the burns and this was after several doses of morphine. I asked that the foley catheter be checked and while I was continually told it was "fine" I was persistent and finally a sonogram was done to ensure its proper placement (or as it seemed at



the time - simply to keep me quiet). The sonogram technician gave confirmation that it was done correctly so from this point forward, my complaints that something was still wrong due to my son's discomfort and instinct as a mother went ignored and we were transferred to Nassau University Medical Center's Burn Unit (NUMC) where he was admitted for treatment.

When the attending doctor at NUMC was reviewing our case, he noticed that while there was an IV of fluids entering my son's body, after several hours the bag that showed what was coming out was completely empty. Coupled with the my son's continued complaints about discomfort in the groin area, it wasn't long before the doctor decided to attempt the foley catheter a third time and in doing so discovered that the second foley catheter inserted at North Shore Manhasset had been done so improperly that the balloon was not even inflated. While I was obviously enraged that the doctors and nurses at your hospital not only messed up the procedure itself twice, then misdiagnosed the "check" and failed to listen to my complaints and rectify this situation, I was relieved that the foley was finally done correctly at NUMC as afterwards for the first time since the incident had occurred my son was for the time being, out of discomfort.

The next day my son underwent a procedure in the OR at NUMC that covered his burns with a treatment called Oasis. This greatly helped with his pain in the burn areas. However, he continued to show discomfort in his groin area and was unable to sleep as every hour or so he was seizing awake in excruciating pain. I pushed to have the foley catheter removed and the doctors agreed that they would weigh his diapers in lieu of this to ensure adequate urine output. Still, with the catheter out for over 24 hours the seizures of excruciating pain continued and it was soon discovered that he in fact had developed a Urinary Tract Infection.

After days of terrible pain, the antibiotics finally helped him. Now that we are home from the hospital, I remember the UTI pain as worse than the burn pain. This is no doubt a result of a procedure gone wrong TWICE at your hospital and I'll hold you three times responsible for this as the sonogram also improperly diagnosed the situation. Do you think this is something that a 2 year old already traumatized by burns should have had to endure?

As I stare at the \$75.00 balance on my account with you that my insurance did not cover I cannot bring myself to give you a single penny for the extra pain and stress your hospital's incompetent care caused my 2-year-old son. At this point, I want my fee waived. I also think that my insurance company should not be billed for payment for the two failed Foley catheter procedures or the sonogram that misdiagnosed the second incorrect placement. Further, I want a case opened to research this matter so that all parties involved are notified of their failure in care in hopes that a situation as such does not happen to another child in your Emergency Room. I expect that this matter will be fully addressed in a timely fashion, and that I will not need to be in contact with my attorneys at this time.



Regards,  
Alicia Assad - Mother of William Assad

**Perspective**

April 19, 2013

On a typical morning as I am trying to get both kids out the door to get Catherine to her school by 8:25am which is 30 minutes away I have little patience for sibling rivalry. This morning, I was ecstatic that I had to tell William to pick up the Hello Kitty bag full of stuff he had intentionally dumped out with a smirk and then apologize to his sister. Waiting for him to pick up every last bead or whatever the heck she had stuffed in there was worth the 15 minute setback because not only was William's goofy and mischievous personality coming back...his mobility was too. This is the first time he has been able to squat down and use both hands to pick stuff off the floor. He also can climb in and out of my bed and on and off the kitchen counter chair. Seemingly overnight he made a huge stride in reconquering the ordinary everyday pursuits that were part of his toddler activity before the accident occurred.

I know I am becoming redundant in saying he is finally on the mend, but it is as though with each passing day and each stride he makes, a bit of the pent up worry and tension I have carried begins to fade. Catherine is due home from school soon and I cannot wait to see what he comes up with to push her buttons tonight. I never thought I would say that....it's funny how your perspective can shift.



Having had two babies come just before the 42 week mark, the end of my pregnancies have been spent hormonal, swollen, bitter and desperate for the onset of labor. Pregnancy is a long journey and when you see your due date come and go and then coast through the 41 week mark you wonder why the torture must go on. Never did I ever think I would be hoping and praying for a pregnancy to drag on as long as possible....but let me tell you last night when my contractions were consistently 3 and 5 minutes apart I was fighting and then thinking, "no....not yet...just a few more days" and eventually I fell asleep and while I am still contracting as I type, these are just more of the harmless Braxton Hicks contractions I have been experiencing since 33 weeks.

I know labor is lurking around the corner but William needs just a little longer to settle in and detach himself from me....and I would like just a few more days to savor the feeling of a baby rolling around inside of me. Yes, my back hurts, I am exhausted and very eager for a strong cocktail but there really is nothing more incredible in life than nurturing life inside your body. Nine or ten months of this is nothing in the scheme of things and now that I am through the chaos of William's ordeal I want to savor what I have left of this experience.

### **Baby on the way!**

April 19, 2013

Looking forward to starting off our first calm and quiet weekend at home, we decided to take the kids for dinner. Somewhere between the parking lot and ordering food, my water broke and back in the car we went without eating to head home.

Because my contractions were around 11 minutes apart and not much more painful than they have been since 33 weeks, I felt I had time so I got my stuff together and took time to snuggle with both kids. Catherine had a thousand questions about what was happening so she could compare my experience to





what her book, "Baby on the Way" says. She thought it was pretty cool that I had belly squeezes and my water broke just like the mommy in the book. She said goodbye and told me she can't wait to meet her new baby brother.

William was in a chipper mood, bouncing around, and when his grandparents arrived was easily distracted. I have not left his side for three weeks and two days. Literally, we have been together 24/7 so I have been extremely anxious about leaving him to deliver. When he was happy and distracted I was planning to sneak out of the house so I found what I thought was an unassuming opportunity to give him a huge kiss and he said, "Bye Mommy!"

And just like that...as if he knew he had to let me go....he went about watching Shrek with his grandparents and I was able to leave the house calm and worry free about my two littles at home.

Currently, I am on the fetal monitor at Winthrop University Hospital feeling pretty calm considering I am in labor. I suppose it is that perspective thing I mentioned earlier. The only thing I am kicking myself about is not eating anything since our dinner was interrupted. I have eaten nothing since 12:00pm so I am starving and while I was initially told I can eat or drink nothing (great for energy to push out a baby) I was just told by my doc that in a few minutes I can go for a walk and if I happen to eat a little something along the way then that's ok., I just can't tell anybody :) I think I have a good doctor!!!!

So with that being said, I am back at a hospital. I had three glorious nights at home to recover from William's ordeal which was a blessing for all of us. Hopefully sooner rather than later and with as little pain as possible I will be holding my new baby boy!

### **Who said the third comes flying out???**

April 20, 2013

....because I hate them. Yup no baby yet. I walked and walked and eventually had to agree to start Pitocin at 4 am. It is now 7:32am...a bit more than 12 hours since my water broke and while I am very uncomfortable, I am still at the cusp of active labor. I was not keen on Pitocin as with Catherine the end result was a section. William was a VBAC, which gives me hope but he progressed much faster than this!



The report from home is that both kids slept through the night like angels. Thank goodness but really!? I have been walking and contracting all night. Fun times.

While things are slow to progress I am hoping that it kicks in real fast and that I get to meet this baby who has now decided to be stubborn. Mamma is very tired, hungry and grumpy.....

### **Henry Edward Assad**

April 20, 2013

Born today, April 20th, at 2:26pm:  
7 lbs 11 oz, 20 inches long



As soon as Henry was born, he was put on my chest and not long after he peed which is a very very good sign. Because he had a normal urine output, he is with me in my room and treated as a normal healthy baby and has already nursed four times.

Tomorrow they will do some testing to look at his ureters and kidneys but for tonight we will rest well knowing he is finally here, healthy and of course looks nothing like his Mom!

### **Small Miracles Happen Every Day**

April 22, 2013

We are home! All of us....together now as a family of five...well...six including Charlie, the beagle, who apparently missed me as much as the kids because he has his head on my lap!

Henry went for his sonogram today and while in utero his ureters were bigger than the doctors and sonogram technicians had ever seen and his kidneys were taking on fluid, there were literally no abnormal findings. I was with him when they did the sono and kept saying, "Are you sure? Check again..."

Let's just say I was hoping for good news...but this is amazing news compared to what I was told time and time again by doctors that I would be facing. While we aren't out of the woods just yet....babies tend to be dehydrated when they are firstborn, so things could show up in the next few weeks, for now there is no surgery and no intervention. Henry is home with us as the normal, sweet and healthy little boy he appears to be.



More updates and details to come...just wanted to let you all know we are all home, happy and healthy. I believe in the power of prayer. Somehow it had a hand in this. Thank you all for your love and support. Xoxo

### **Lesson from a 2 year old.**

April 23, 2013

For so long I worried...William was always very attached to me so I was convinced that when the baby came he would have a difficult transition. Then his accident happened which made us inseparable to the point where I couldn't be 5 feet away from him let alone in another room. This of course was always heightened when he was uncomfortable or in pain, and while he was getting better each day I was tortured about leaving him to have the baby.

After my water broke and I settled the kids into the house and William said goodbye to me as though it was no big deal - as he would have before this whole ordeal began, I was in awe. It was as though he knew that he needed to give me space. He knew that it was time for me to go and focus on bringing his brother into the world.



And so it seems that he continues to amaze me with his understanding. He has been nothing less than

excited about his new baby brother who he calls "Hengwy." He loves to kiss his head, touch his toes and he thinks all the noises he makes are "very funny." While I expected him to be jealous and territorial, he instead is happy to find a snuggle spot around Henry when he is nursing and the three of us hang out as we have been for the past month only Henry is real to us now and not just a stranger in my belly.

Henry is a very sweet and quiet boy. From the moment he was born, I was worried that he wasn't crying loud enough. Even when he is hungry or needs a diaper change, his cues are much more tempered than I remember of Catherine and William as infants. Given the boisterous personalities of his older siblings, I suspect that Henry will be the more cerebral, thoughtful and quiet one of the bunch but who knows it's kind of early to tell...and nonetheless fun to guess.

It certainly is busy in my house and there are times when I'll admit it is overwhelming...a 4 year old who needs the attention she hasn't had from me in over a month now, a 2 year old who has been through a traumatic event and is still healing, an infant, and then there is Mom who has entered this all sleep deprived and is having a hard time catching up co sleeping with a toddler and infant. Still, this all seems manageable given what we went through with William. Nothing is better than having my family all in the house together and healthy. While I would like to say that everything happens for a reason, I cannot think of a way to justify the pain that I had to watch my child go through.



Still, I suppose I can try and find the good in the situation and that most certainly is my ability to savor and appreciate the present moment for as chaotic as it seems I know I will never have this time back again: Catherine suddenly a big girl who insisted this morning that breakfast had to wait because she needed to fold her baby doll's clothes, William, the goofball, who thought it was really funny to eat dinner with his hands over his eyes while I fed him and Henry who is so tiny and perfect and delicious with his newborn smell.

It has taken three kids and a rough month for me to learn the art of focusing on the present. Now as I kiss Henry's full head of dark hair, I remember doing the same with his brother and sister and while I always cherished the infant phase I have regrets of wanting it to go faster because I was so tired and overwhelmed. This time I am more tired and more overwhelmed but it can drag on because for today my whole family is happy and healthy.

I realize from the way William has reacted to Henry's homecoming that I was afraid of being able to love and care for another child. I felt that in loving and nurturing Henry I was taking away from the love that I needed to give to William and Catherine. Somehow when you have another child, your heart grows. At least mine feels as though it has swelled and I am able to love my children more than I ever have. Maybe this has more to do with seeing my family through a traumatic event followed by a 19 hour labor - somewhere in there I realized my capacity to cope, endure and love was more than I ever knew it was.



Regardless, it has been William's reaction to Henry that has pieced it all together for me and with that I will sign off and sneak back into bed with my boys.

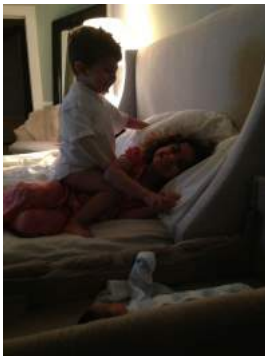
## Normal

April 28, 2013

That is what life finally seems. Sibling quarrels over whether to watch Shrek or Doc McStuffins, negotiations about how many veggies need to be consumed off the dinner plate, dishes, laundry, changing diapers, arguments over weather appropriate attire, Sunday eggs, bacon and church and even an hour of TV on the couch with Eddie while all three little ones were asleep. This is the normal I was hoping for last weekend as we ventured off to dinner on Friday night but my water broke signaling the beginning of "our next hurdle" given what we were told was imminent with Henry's ureters. While there are still some balls up in the air about what exactly will happen with Henry as he has some more tests this coming Wednesday, we got a week to adjust and bring him home "healthy" and a weekend of "ordinary." After William's ordeal, the "birth/Henry" hurdle was a 2.5 on the Richter Scale and we are confident that whatever the future of Henry's situation holds it will be completely manageable.



Normal is what I think Eddie and I have been longing for since this all began and there were times when everything seemed so chaotic, we wondered if life would never be normal again. For so long it felt as though William's wounds would always be open and painful, that we would always be doing daily dressing changes and hearing him cry out, "I'm all done, I'm all done!" from the moment we would start. We went back to the hospital for burn clinic on Friday and the doctor told us that the dressing changes are over. For two weeks, he is to wear normal clothes and take a bath as a normal 2 year old.



The only challenges are his lotion massages on the burn sites 3-4 times a day and the sunscreen and hats he needs the moment he walks out of the house and eventually the special "shirt" he will be fitted for and wear 24/7 to hold the grafts in place. I'll take them...and I think he is quite relieved as well. Endless it seemed I would be living in a hospital but in the scheme of things, the 15 nights I spent drifting off to the noise of IV alarms and Shrek were not really that long given the situation. Now that I am home for good and in my bed it all seems a distant memory. On Monday I resume my normal routine of having two...well now three kids out of the house by 8am followed by groceries, dance class runs, doctor's appointments, "am I really out of toilet paper already," and "what am I going to put on the table for dinner?" dilemmas. I never thought I would actually crave this routine so badly.

It's funny...last Friday night, after we had rushed to the hospital "because third babies come fast" only to find out I was only 1 cm dilated and was sent out "walking," I found myself seated across from Eddie while we scarfed down stale turkey sandwiches. I was thinking, "wow, life actually seems normal - just me and Eddie together having a normal conversation over dinner on a Friday night." Somehow I wasn't focused on amniotic fluid or the contractions I was having or how delivery would go. William had let me leave without a blink and knowing he and Catherine were tucked in under a roof with both sets of grandparents, for the first time in weeks I wasn't worried about either of them. I was in labor and again in a hospital setting, but for a while the dust seemed to settle, my shoulders

relaxed down my back and everything seemed calm in this stolen moment.

Don't get me wrong, reality soon set in when my labor didn't progress and my fear of repeating the CEsarian I had with Catherine was brought to the surface at the insistence of Pitocin. I was so terrified that I managed 9 hours of my 19-hour labor riding the waves of artificial contractions without more than my iPod and a few back rubs until I was 8 cm dilated and could no longer bear it. "Restful" after this was the pain free 40 minutes where the epidural actually worked (after not working with Catherine or after two tries with William) and I drifted off before I was able to push Henry out in three tries. "Relieving" was the moment Henry was placed on my chest after having suffered two miscarriages and almost losing him before Progesterone kept him snug inside of me for 39 weeks and 3 days. "Miraculous" was when Henry peed all over me after I was told that his urinary tract wasn't working properly and he would need an immediate surgery.

I think that while I have grasped at reclaiming "normal" since William's accident occurred, now that we are settled back at home as a family, I am realizing that I haven't been normal since the first miscarriage that knocked the breath out of me last April 12th, 2012. I think it took William's four hour skin graft surgery taking place on the 12th day in April of 2013 for me to acknowledge this. The collision of these two events exactly a year apart brought me to the lowest I have ever been in my life. Since then, the fears, anxiety and guilt I have carried has slowly lifted as I navigate my life with both of my boys on the road to recovery and eventually perfectly healthy - because they both will be. Yes, finally, life feels normal...or maybe normal isn't the word. Perhaps given its abundance of blessings it can never be normal again and I will never be the same again. Now I see the love that surrounds me in so many ways and I think that my life now is extraordinary given its capacity for so much love and so many blessings.



### **The boys...doing well : )**

May 2, 2013

Henry is the sleepest baby I have had. That little guy will sleep through all the commotion in the house and while he should be nursing every 2-3 hours, prefers every 4-5 hours. This is great for Mom but not his weight gain so I try to wake him to eat. I strip him down, wipe him with a wet cloth (mean I know) and still he is content to sleep away in my arms until he decides it is time to eat. This of course has been the case with the only exception being yesterday when I had a photographer at the house to get some of those really sweet mushy sleepy newborn shots. He refused to fall asleep!!!! While we eventually got a few snaps, he proved to be the photographer's most difficult client and as soon as she left was sound asleep again.



We did get good news from the pediatric urologist - that his kidneys look "beautiful" which means whatever fluid was in his kidneys in utero did no damage and isn't there now. This is a relief because kidney damage was the big fear and the urgency of the surgery he was supposed to have following birth. His ureters, however, did show up as enlarged yesterday and we are going to do another test to take a closer



look at things in the next week or so. I think the worst case scenario with this is a surgery around 6 months to a year or he could possibly outgrow it. Given the way things have played out thus far we are hopeful the latter could happen so keep your prayers coming!!!

### **Resilience...and Henry, my one month old "miracle baby."**

May 20, 2013

The moment William's accident happened, I was already tired and stressed out. Thirty six weeks pregnant and headed out the door with Henry's sonogram in hand that noted the enormous size of his ureters and the beginnings of kidney damage, I was distracted but pulled back to reality as I heard the babysitter scream. With the rising sensation of fear and panic in my chest, I ran back into the kitchen, and saw the babysitter running to the sink with William in her outstretched hands. I grabbed William from her and when I saw the heat and steam rising up off of his clothes, I attempted to rip his shirt off not realizing that his bicycle helmet was still on. I had to fight the adrenaline rush and slow down in order to unbuckle the strap and remove the helmet, then peel off his shirt. In this eternally slow and clumsy moment, the severity of the situation became apparent as the skin had almost completely melted off half of his face, neck, chest and arms. As I tried to grapple with what this meant, I couldn't help but feel as though I was helplessly sinking into a dark hole. Maybe I wanted to sink into that hole and disappear because I knew what I had to do, but didn't want to. I really just wanted to run away from it all.

Not wanting to shift from this moment because I knew the next would be even harder, I looked up, saw Eddie standing nearby and was relieved to be able to give him William. As I handed him off, Eddie and I made eye contact and had an unspoken dialogue that said, "knowing how long it took the ambulance to get here when he had his stitches four weeks ago, we need to just get in the car and get to the hospital," and with that Eddie headed for the car. I turned around with the intention of finding my purse and when I faced the babysitter, I paused but the room continued to spin around me, and suddenly the fear and panic escaped my body as I screamed, "Nooooo! I can't handle this!" and collapsed. The babysitter caught me, picked me up and held me by the shoulders while she shook me and said, "Alicia, listen to me - you need to be strong. You need to get William through this and you can't let yourself go into labor now." With that, something in my perspective shifted and I found my way to a stronger place. I regained my footing, calmly walked out the door and climbed into the car next to William so I could hold the car seat straps away from his raw, oozing skin as Eddie dodged rush hour traffic to the hospital. While I was more scared and helpless than ever before in my life, I stayed focused on what I needed to do and that was comfort my terrified son. I pressed my cheek to the unburned side of his face as he screamed so I could whisper in his ear over and over again, "Mommy loves you so much, I know the ouchies hurt but you are going to be all better soon. You are going to be alright."

I was so collected and focused that when I rushed through the emergency room doors, and said, "my son is burned please help me," a few doctors and nurses looked at me and then carried on with what they were doing. I repeated, "someone please, I need help...my son." No response, they all were in deep conversation and the pregnant woman running with a shirtless, crying two year old in her arms could wait. Before long I was arms length from the check in desk, and pissed off that no one was paying attention to me so I screamed, "I need help now...my son has been burned and I am very



pregnant and having contractions and at risk of going into labor at any moment!" Instantaneously, I was swarmed by a group of people and whisked off to a room where I sat on a stretcher with William on my lap and before I blinked they had layered gauze on his burns, put an IV in his foot, hooked up blood pressure, heart monitors, inserted the foley catheter, started morphine and roughly explained to me that the size and location of the burns were cause for grave concern.

Throughout the remainder of the ER experience, the transfer to the burn unit, that first fear filled sleepless night with William followed by a two hour surgery the next day, then six days in the hospital, a week home anticipating the inevitable second surgery and recovery from skin grafts, six more days in the hospital, then adjusting home with a wounded kid who needed daily dressing changes and constant affection, an attention deprived Catherine who was trying to digest Mommy being in a hospital again to have the baby, breaks from it all only to go to my OB to monitor the baby that needed a surgery by three days old and may or may not need to be induced at any time if my fluid dropped, three nights of non-hospital rest followed by my water breaking and a 19 hour labor.....

....I was strong. I was resilient. I handled what I needed to. We got through it and each day now, our situation is better...more manageable...and constantly we repeat, "we were so lucky...it could have been so much worse.....thank goodness his face will be ok, twenty years ago he could have died, we are so lucky Henry held out until William's hospital stay was through, we are so lucky Henry didn't need a surgery right away..."



But now as life is continually better and I recognize more blessings in my life each and every day I find that I am struggling harder than ever to stay strong and resilient. Why now? The way I look at it is that resilience is something you need to work hard to maintain. I liken resilience to a muscle: the more you work your muscles, the stronger they become. The more you work at resilience, the stronger it becomes, and as with a muscle, the more consistent you are at this, the easier it is to maintain your strength and tone. These days my resilience should be as bulky as body builder's muscles but still, I cannot help but feel as though my "resilience muscle" is completely overworked and fatigued. As when your bicep muscle is maxed out and burning and quivering and you are fighting your for say, "just one more bicep curl..." I am willing my resilience to "help me keep it together" and "stay positive" but some days, just as some workouts, are easier than others.

I suppose what gets me through these moments of exhaustion and sadness is simply allowing myself to have them. Holding it all in is certainly not healthy and I am discovering that the most useful tidbit of information I took away from my studies of positive psychology involves something called the Losada ratio and Barbara Frederickson's broaden-and-build theory of positive emotions. Broaden-and-build suggests the necessary role of both positive and negative emotions in our lives. We experience these emotions every day and while a negative emotion such as anxiety leads to a survival response (fight or flight), a positive emotion, such as hope, can allow us to see the light at the end of the tunnel and play a long term role in psychological resilience and flourishing. If we are "supposed" to have both positive and negative emotions and the Losada ratio suggests that a healthy balance of these emotions is 3.1 positive to negative then I constantly remind myself that the negative emotions I process are normal, expected and as long as I keep them "in balance" I will be ok...I am moving forward and yes, I am healing so ultimately, I am adding fuel to my resilience tank. At least this is what I tell myself these days...



These days, William's journey continues to take turns that surprise us. Two weeks ago when we took him to burn clinic, we were told that soon after we get his "special shirt" fitted that holds his grafts in place (it should be here next week) we should start considering procedures to help with the scaring of his grafts. These procedures, among them microdermabrasion, laser treatments and Z-plasty are done in the operating room. Hence, William needs to be put under and relive the trauma of being in a hospital and healing from open wounds four or five times, maybe more depending on the severity of the scar tissue. Overwhelmed by this, we went to the city for a second opinion and those doctors suggest we do nothing and accept that he will be badly scarred and his movement might be restricted from the tightening of the scar tissue. We are still researching and gathering opinions, but I think our decision will fall somewhere between allowing time to see how his body heals on its own and being proactive to give him every advantage to heal - even if that means some invasive interventions in the next year because the scar tissue is already beginning to restrict mobility in his neck.



While he detests his "lotion massages" that I do twice daily and itches violently at night to the point where I need to hold his arms while he is sleeping and console him back to sleep when he yells out from the discomfort, William is as goofy, rambunctious and outgoing as he ever was. Diaper changes are tough because he gets raw spots on his still healing behind, but he cries, deals with it and moves on to either ride his bike, hunt down a fun new toy from Catherine's room or "see baby Hengwy." I think his personality and attitude are what help pull me through those moments when I want to feel so sad and angry about what he has and continues to go through. I used to love bath time in my house where I had two "naked monkeys" running around....but now it is the hardest time of the day for me because I need to flex my "resilience muscle" really hard to fight back the tears I want to cry when I see William's beat up little body. I realize this will all look better with each passing day but he will never be perfect...as he was when I brought him into the world. I think Henry in his sweet infant perfection is a reminder of this. We bring our babies into the world and then life happens....and lately I am working on accepting that there is nothing I can do to erase everything that happened.

Henry had a sonogram at two weeks old where it showed his ureters were perfectly normal but given the size they had been while in utero and a thickened bladder wall (which suggests damage) I was told to take him for what is called a VCUG. This test is an X-ray taken after dye is inserted into the urinary tract via a catheter (how I love these...) to essentially see where the urine is going and allows a closer look at the potential areas of dilation. The doctor performing the test didn't give him a UTI (phew), and was able to tell me that indeed the ureters were now perfectly normal and there was no kidney damage or reflux, but still he still had a dilated urethra and thickened bladder wall. But "with a really good urine stream, this is a very confusing and contradictory finding." I left the test assuming that this would mean constant follow up until they figured out what the cause was and had a week of anticipation before the follow up with the pediatric urologist, Dr. Hanna. At our appointment this past Wednesday, Dr. Hanna entered the room and said, "Ok, let's see what this little trouble maker has been up to." He studied the X-ray for a moment and muttered, "he most definitely had a valve and at some point between your last pregnancy sonogram and the one he had after birth, he corrected it." While he stepped back, folded his hands across his chest and continued to stare at the findings, I suggested, "so Henry's technically not a trouble maker." To this, he replied, "no, I still consider him a trouble maker...just a brilliant one." Eddie and I looked at each other, back at him and asked, "how often does this happen?" to which he replied, "I have been doing this for over thirty years and while I

have heard of this happening I have never seen it happen myself." "So you mean we have the miracle we have been praying for?" Eddie suggested and as Dr. Hanna was snapping photos of the X-rays to report his "rare finding," he said, "yes, I suppose you could consider this somewhat miraculous."

While we still need to do a procedure in the OR when Henry is six months old to make sure the rest of the dilation dissipates and there is no residual valve left behind to give him "a clean bill of health," we are optimistic that this will be the final chapter of his PUV. Henry's situation was indeed as severe and worrisome as the sonograms I had during pregnancy indicated. Looking back that must have been why I was checking in weekly with Dr. Hanna via his cell phone on the progress of my sonograms. Now, despite all that worry, and I suspect because of all the prayers from so many loving and supportive friends, family and even strangers...I have a thriving baby boy who is exactly one month old today!

So, I think I will end this very long post with the amazing news we received: Henry is a "brilliant troublemaker" who I am now certain is "perfectly healthy" and after his procedure at six months I will not need to spend another moment worrying about his urinary tract or kidneys or handing him over for another test. His situation will be but a small bump in the road. Yes, William's road to recovery continues, but I have been prepared since December to be focused on the health issues of my son at this given moment in time. William might not have been the son I anticipated to be in and out of the hospital and sleeping in my bed but life is full of surprises. It is certainly filled with miracles...big and small....and as long as the good outweighs the bad in any situation in my life, I'll muster up the strength to keep working at my resilience to keep on keeping on....



PS - I am perfectly capable of properly citing the positive psychology terms I referenced above but I am out of time as William is eager to go outside on his bike now that there is a break from the rain. If anyone wants more information about resilience, the Losada ratio or broaden-and-build please let me know!

**Just tell it like it is...**

June 5, 2013

"Go ahead, try it on - this is your special shirt. It's silver like a knight's armor - you can slay the dragon in Shrek wearing this." William said nothing, peered at me under his eyelashes with a pout on his mouth and put his head down on my lap. "Why are you hiding? I think this is a pretty cool shirt...and it is going to help your ouchies get better really fast." Again, he said nothing but sighed and turned his head, still pressed in my lap, to the other side. "Ok, I think that lollipop you got from the front desk is pretty tasty. I bet you would like another one, right?" My bribe worked like a charm as he finally responded, "Can I have a purple one...and a blue one?" to which I replied, "Yes, if you put your new special shirt on, I promise you can have two more lollipops when we are done."

With the prize of lollipops in sight, he allowed the technician to pull the very thick, custom designed and manufactured in Germany turtle-neck, long sleeve and skintight shirt on his body to cover and support his burns with the hopes of minimizing scar tissue. This "compression garment" will be his fashion accessory 24/7 (with the only exceptions being bath time and swimming) for the next year. Upon first sight of this shirt, my heart sank as I thought of the recent heat waves and the sweltering weather they might be indicative of for the coming summer. The heat paired with this suffocating shirt on William's little body that is already lacking sweat glands where he was grafted (11 percent of his body) is a recipe for overheating and discomfort. The time and fights it will take to get this garment off and then on again in the mornings for his lotion massage, then at the pool if he swims, at bath time, etc. was the next fleeting thought. Then as I looked at William's quiet, sad face peering back at me as if to say, "Mom I know you are trying with your silver knight nonsense but this shirt is terrible, and I am not happy about having to wear it, but I will because you are insistent."

Four Dum-Dums lollipops later (this is the rare instance where I can be grateful for artificial flavor, coloring and high fructose corn syrup) we were headed to the car. William was silent except for his unusual request to be carried as he always insists on doing everything on his own. When I strapped him in the car seat, he turned away when I tried to kiss his cheek so I just got on with our journey home. In the rearview mirror, I couldn't miss his slumped shoulders and downturned hat that I knew was concealing a still pouty face. "Ice cream. How about some ice cream - would that make you feel better?" I suggested thinking a little more sugar could fix this situation. This time, he didn't bite the sugar bait so I let him be. As we approached town, I asked, "Are you sad because you don't like your new shirt?" He picked his head up, glance at me through the mirror, and put his head back down. "Ok, I know you don't like the shirt and that is alright. I understand. I don't like it either. I am sorry you have to wear it. I am sorry this all happened but the doctor's say this is going to make the ouchies heal better," and I continued this banter, more to convince myself of why I was torturing my son any further than to remedy a two year old's pout. In the ensuing silence, I drifted off in my mind to my pity party about how this all really sucks and I wish it was all over for him already but my rumination was interrupted with, "I want banilla ice cweam" and so we stopped for the vanilla ice cream we both knew wouldn't make the shirt situation any better.

William's personality has been back with a vengeance the past month. Nothing has set him back - not his constantly itching "ouchies," lack of sleep or his follow up visit to the burn clinic - he sailed through it all with a pep in his step and high fives for everyone along the way. I was so struck with fear that this was going to be a big retreat he wouldn't easily pull out of. While William's silent treatment came to an end with vanilla ice cream and my honest acknowledgement of the situation, his mood didn't fully shift until Daddy's suggestion of going to "play golf." In the past month, motivated by the need to keep up his activity to prevent the scarring from restricting his mobility, Eddie has been taking William to "go hit gwalf bawls" - an activity he loves. And so to this Mom's relief, it was Daddy who swooped in and saved the day. While the boys were out doing their thing on the driving range, Catherine and I did some gardening and nursed our babies (she has taken to modeling my mothering skills with her baby doll she named "Catherine"). By the time dinner was on the table, William came bounding into the house excited from golf and in much better spirits. How relieved I was to face a two year old's pout about how many bites of broccoli needed to be finished before leaving the table and later about not



being allowed to jump in my bed.

## **The Beauty of Scars**

July 14, 2015

Two years ago, my son William was burned by a pot of hot water. He joined thousands of burn victims who take the arduous journey to recovery from such an injury. That is - those who are lucky to survive. Every day, I am grateful that William is a burn survivor.

Yes, my son survived the scald burn covering 16 percent of his body, but he carries extensive scars from his injury, so he continues to face adversity. He overheats easily from the lack of sweat glands. We live with the fear that he may lose mobility as his scars shift. Most of his scars can be concealed by clothing, so in a long-sleeved shirt with a collar, his injury can almost go unnoticed. Mostly William has a choice to conceal his scars (one that many burn survivors don't have). But there are moments when he doesn't want to be burdened by weather inappropriate clothing, or his clothing shifts. When his scars are seen, he needs manage when others point and stare, or when someone says (and yes, this has happened) that he is "disgusting and gross." For me to help my son manage the emotional scars of a burn injury, I needed to work at managing them myself.

In July after the accident, William received his compression garment, a suffocating, skin-tight, long-sleeved turtle shirt designed to compress his all of his scars. Though I hated that compression garment with a vengeance, I made William wear for 23 hours every day because it was the only tool I had to make his scars better besides twice-daily scar tissue massage. I was determined to fix what was wrong, so a compression garment, massage, and time to heal were not enough for me. This led us to seek a second opinion from another burn specialist because both Eddie and I wanted to fix him. My second opinion doctor was the first person who pointed out that our son was scarred. He said, "We don't like scars because they are ugly, but in this case, you need to accept them. Be grateful your son is alive and move on."

This was hard news to digest, but we both needed to hear it because if William's scars were a part of who he was, we needed to love his scars too. Though the angry pattern of hypertrophic scars running down his neck, across his chest and down his right arm was a roadmap of pain and sadness for me, I fought to maintain the perspective that his scars are beautiful because they are symbolic of the strength he showed through adversity. William's scars remind me of his bravery. Because of what he had to endure I have seen the strength of his spirit.



## **Determination VS Gratitude**

July 22, 2015

In my last post, I mentioned that William's scars came to remind me of his bravery. Still, my resolve to love his scars was tested each time William told me he hated his ouchies. Though I always reminded him his scars show us how brave he once was and are a beautiful part of him, I couldn't ignore several questions. Is doing nothing really the best thing for William? At what point do you just

throw in the towel, focus on blessings and accept what was happened? At what point do you know you have fought hard enough for your child's well-being?

Eddie and I couldn't overlook the fact that at William's young age, reconstructive surgery could have very good results. When friends introduced us to a pediatric plastic surgeon at a birthday party, it became clear that doing something was the best decision for William's well-being. At three, William did not waiver from his desire for surgery "to make my ouchies go away" even though I explained to him that the doctor was going to cut him open, take out some (not all) of the ouchie and then sew him back up again. I was brutally honest in reply to his question, "Will it hurt?" saying, "Yes, William, it is going to hurt." I wanted him to know the truth. I also secretly hoped he would want to back out and not go through with the surgery. Yet William never wavered despite my warnings. He would always reply, "I don't care Mom, I want them to go away."



William's scar excision surgery lasted several hours. When he woke up from the anesthesia with seven raw incisions under layers of bandages, he was devastated to find that the ouchies were still on his body. This is the first time I ever saw William depressed, and I felt that I had let my boy down. But by this point, I was confident we had done all we could for him so I forged ahead through the maintenance of his new wounds. The surgery had successfully reduced the surface area of his scars by 30 percent.

### **Shirtless and Courageous**

July 27, 2015

I wish there weren't moments when I still feel a desperate urge to fix William. But there are many of them, especially as he grows and becomes more aware of his appearance. William has started to notice the way others react to him. Helping him manage socially is the most recent step in his recovery. At the beginning of the summer when I knew William was going to be changing in the locker room at camp around a group of mixed-age boys, it was clearly time for him to have the right tools to cope in a situation where he could not conceal his scars. I started researching the best way for him to handle the attention we both knew his scars would get. The Phoenix Society for Burn Survivors has been a valuable resource for this.

I watched a webinar about a teacher who learned how to cope with scars from a severe burn injury she suffered in a car accident. She explained that she dealt with social situations by being open, honestly answering questions, and quenching curiosity. So when William came home from camp one afternoon in a mood that clearly signaled his scars had been an issue that day, I had something concrete to tell him. "William, when someone asks about your ouchies, just tell them you were burned by hot water and you have scars. If it is no big deal to you, then it will be no big deal to them." I caught his skeptical glance under his long droopy eyelashes but finished it off with "Please try it. I think it will work."

A week went by with no discussion about his ouchies until the afternoon we were heading home with new swim team uniforms. William was insistent on participating along with Catherine in the swim meet that very night. I was proud of his determination to jump in the pool and swim a whole long lap



in front of a crowd. But then, he said something that terrified me:

“Mom, I want to swim without my swim shirt tonight just like the other boys.”

To which I replied, “William, if you swim without your shirt, everyone will see your scars. Are you sure about that?”

“Yes, Mom. A boy asked me about them today and I told him about my ouchies just like you said. Then he left me alone. So I can swim without my shirt at the meet.”

This is when I started to panic thinking this is too much too soon.

What about the crowds....everyone will see him...he doesn't know how much attention he will get....but goodness, he is being brave. Clearly, I need to find some courage myself, so I replied,

“Of course William. If you do that, I will be so proud of you.”

All afternoon, I had a knot in my stomach. I gave him plenty of reasons to back out of the race or swim with his shirt on. I wasn't completely confident when I assured Eddie about letting him go shirtless for the first time in front of a crowd of people. But I said, “We can't squash his courage, regardless of how scared we might be.”

The long and short of it is that this happened:



### **Growing Through Adversity**

August 4, 2015

We all face adversity at some point. While adversity can be a painful experience, it can also lead to growth. New research suggests that remaining open to future possibilities might be one way we can ensure positive growth occurs. Read more about this in my article published on the [Positive Psychology News Daily](#) website.

### **Allowing the Experience of Joy after Loss**

August 6, 2015

“To love someone fiercely, to believe in something with your whole heart, to celebrate a fleeting

moment in time, to fully engage in a life that doesn't come with guarantees – these are risks that involve vulnerability and often pain. But, I'm learning that recognizing and leaning into the discomfort of vulnerability teaches us how to live with joy, gratitude and grace.”

~Brené Brown, *The Gifts of Imperfection: Let Go of Who You Think You're Supposed to Be and Embrace Who You Are*

I have given birth to three babies, and I have lost three babies. For a seventh time, I am pregnant. I have just entered the third trimester and this is the first time I am acknowledging my pregnancy in an official way. Yes, those who see my ripely pregnant belly know I am expecting. But this time around, I have made every effort to be nonchalant about the fact that by the end of October, I might be holding a new baby girl in my arms.

One can easily assume my avoidance is predicated on the fear of explaining another loss. Yet this is not the case. When I have been open honest about my losses, I have found an abundance of women who have been there too. Since the courageous woman who shared her miscarriage experience with me when I was first grief stricken three years ago, I have known I am not alone. Besides, no one could possibly be a harsher critic than I have been on myself. I am very familiar with the shame and blame game, but after grieving each loss, I made the choice to move on. There are so many unknowns surrounding pregnancy and it is rare to ever know for certain what causes a loss.

At least this is what I was told by my doctor who had to console me after I lost my last pregnancy in the second trimester. This is the doctor who gave me the green light to finally celebrate because the ominous blood clot had passed without harming the pregnancy. After seeing a perfect baby dancing on the sonogram screen, my husband and I acknowledged our suppressed excitement about the fourth baby we always dreamed would complete our family over dinner at our favorite restaurant. This celebratory experience made the pregnancy real and our emotional attachment more vulnerable. I wonder if the joy we so recklessly shared is what made our trip to the ER a few hours later so painful. The taste of delight still lingered in our mouths, yet our hearts were in ruin. We discovered we were having a boy when he slid painlessly out of my body into the palm of my hand at home. I pleaded with my doctor to understand why our baby was no longer thriving in my womb and instead lifeless in an old cigar box on my lap. His tone was full of compassion as he explained, “Alicia, as doctors we hate to admit it, but there are so many unknowns in obstetrics. I am sorry for your loss. I am sorry I mislead you and that I don't have the answer to why this happened.”

In a world of uncertainty, I am hesitant to share my good news because I am afraid of experiencing joy and therefore becoming vulnerable to the devastation of loss. Posting a sonogram photo will evoke your excitement. Your congratulatory remarks will remind me that underneath my armor of hope and optimism, which proclaims, “regardless of what happens, I will find my way to growth” is an irrational and undeniable attachment to this baby. Not only for me, but for the sake of my daughter, I want this pregnancy to have a storybook ending. She is old enough to understand the disappointment of loss and tells me often, “I really hope this baby wants to stay and be my sister.” Those of us who have lost babies and are stronger because of what we have endured don't want to be. I don't need another story to tell and I most certainly don't want to answer Catherine's questions about why our babies are angels in heaven. Further, I am terrified of physically recovering from another loss because the last time I had two surgeries and eventually a dose of chemotherapy to rid the remains of the pregnancy. They suspect it was Placenta Accreta but all they tell me for certain is that I am lucky to have come through it all with my uterus intact.



Why on earth would I try again, you wonder? After all, I have three healthy children to hold and be grateful for. My dear girlfriend asked how I found the courage to do this again (a kind way of relaying her fleeting thought that I am certifiably insane). To this, I answered, "Though it was an incredibly painful experience, it was beautiful too. Even if only for a moment, even if he was too tiny to live outside my womb, I held my baby boy. If I erase the pain, I lose out on a beautiful lesson about hope. I am more resilient because of his brief presence in my life."

Daily, I must remind myself that from my adversities I have grown and because of the women who have shared their painful stories with me, I have endured. Therefore, it is time for me to be honest and open about both my fears and my joys - not only for my own wellbeing but for those who are walking the journey of pregnancy after loss along with me. I suspect that if this all ends badly, it will be painful whether or not I acknowledge my joy. But if in October, I am awake in the stillness of the night nursing my baby girl, I will want to reflect upon the magical experience that pregnancy can be. Knowing this is my final pregnancy, I will wish I had savored the miracle of life dancing within my womb.

So in a moment of vulnerability, here is the sonogram photo of my baby girl and the public declaration that even if only for 28 weeks, 5 days and a few hours, there has been life in my womb. For this, I am filled with gratitude and yes, joy. Your congratulatory remarks are welcome, because I am finally open to the experience of joy again.

### **Your Story is Only as Beautiful as You Allow it to Be**

August 20, 2015

Since telling my story, I have received an overwhelming response. Friends who are old, new and even strangers have met my vulnerability with encouragement, compassion and some very personal stories. These stories were generously shared with me not only by fellow parents of burn survivors or women recovering from pregnancy loss, but by survivors of adversity I have not experienced such as cancer or divorce. I have also been applauded through words such as "strong" and "inspiring." This is humbling, especially when I recognize the incredible strength among the sources of these compliments.

The persona I present to you through writing is inspiring because I tell of my adversity through the lens of positive psychology. Several times along my journey, my struggle has seemed insurmountable. In these dark moments, my solace has been the thought that our negative emotions exist for a reason and sometimes we need to acknowledge them. Yes, there are tools we can use to fight our sadness, grief and anger but it is important to process our true emotions because we can only mask or numb the negative for so long before it manifests in maladaptive ways. I look back at these ugly but authentic moments I have had with compassion because we all struggle sometimes. Then, I intentionally focus on what I have gained from adversity, because this perspective allows growth. I am a careful storyteller not because I want you to view me in a particular light, but because this is what helps me move forward with optimism.

### **I Didn't Believe in Rainbow Babies**

October 12, 2016

Just as we need to actively fight despair, we need to work at allowing the experience of joy.

After a year of savoring and reflection, you can read my most recent article published on: [Huffington Post](#).

### **The Stories We Tell: Resilience Gained Through Positive Narrative.**

January 10, 2017

Writing has helped me cope with both the ordinary chaos of motherhood and a crisis.

Read about it on [Huffington Post](#).

### **An Anniversary of Trauma Brings Hope**

March 27, 2017

March 27, 2013 is the night I ended up in an ICU Burn Unit with my toddler son and since then, I have noticed a ripple effect of change in my life.

For a long time, I thought that pot of boiling water crashing down is what initiated this shift. Technically, it did....but now, I SEE it all differently.

The night doctors warned me William might not make it, I was 36 weeks pregnant. Panic continued to pull at me and I almost tumbled down the rabbit hole of despair. But I DID NOT want to go into labor in with a baby who needed surgery at birth, so I sent an email to my girlfriends asking for the help I knew I needed. After realizing I wouldn't have to face the situation alone, I was calmer. I climbed into bed with my boy and snuggled him until the sun came up because at the very least, I had LOVE.

From this vulnerable moment in the hardest experience of my life, my writing emerged in the world.

That email and the updates I sent in the days that followed eventually became a blog to keep friends and family updated on the wellbeing of my boys. In the aftermath of our month-long crisis involving the collision of health of my boys, I created the website BeautifulCrisis.com to share my thoughts on how we can overcome adversity with resilience.

I have continued to write and now that my life has gone back to "normal," I have been contemplating how we can maintain wellbeing not only through adversity, but in the ordinary chaos of motherhood.

This transition made it clear I would need to create a new site where both themes fit. I've been procrastinating on this goal for a while now, but when I realized the anniversary of "the accident" was rapidly approaching (anniversaries are good at dragging up old dormant emotions) I realized I just HAD to launch my new site TONIGHT.

See, I spent a lot of time in grief and guilt wishing I could erase the pain my son endured and restore him to the boy he was before his injury.

However, in a healthier place that is ACCEPTANCE, I have learned to acknowledge what is sad, hard, frustrating and scary....and then CHOOSE what is joyful, beautiful and hopeful.

Yes, there are ALWAYS blessings; we just need to look a little harder to find them sometimes (most especially when we don't think they are there).

My son is a survivor and inspires me every day to make something beautiful of what we endured. So I snuggle him (6 is not too old for that yet) and I tell him how much I love him CONSTANTLY. I believe I am the luckiest mom in the world because he's mine...he's STILL here to snuggle and love....

Then I write.

I'm celebrating four years of survival with the launch of my new website [AliciaAssad.com](http://AliciaAssad.com). It's filled with the story you are already familiar with, along with new dreams and the hope that I can continue to write my way back to WHOLE, regardless of what tomorrow brings.

For now, life's pretty darn good...I've attached a photo to this post, which might suggest my biggest concern about William these days is that he REFUSES to get a haircut!

Here's to the invaluable lesson I learned in an ICU Burn Unit:

At the very least, we always have LOVE...and sometimes showing up with a snuggle of love is ENOUGH for us *and* our kids in any situation.

xo

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