

National News

March 7, 2022

April 8, 2022

Feisty Little Man Impatient to be Born

National “Nash” Abraham Boekweg, ever so impatient, was born today March 7, 2022, at 24 weeks. He weighs one pound five ounces and is 12 inches long. He has a long road ahead of him in the NICU that we certainly did not expect to have to tread but he is beautiful and perfect, and we love him more than we can even comprehend.

Welcome to the world buddy. Daddy and I are obsessed with you and have already decided that you can have whatever you want for the rest of your life.

A Gentle Touch

Update on the Nash potatoes: he is doing well. His ventilator is set to 21 percent oxygen which is what you and I breathe so he isn't requiring additional oxygen. His lungs look good for how early he is, and he is maintaining his blood pressure well. We got to touch him gently and he immediately knew his daddy. The only purposeful movement we have seen is when Abe touched his hand and he reached out and grabbed his finger. They already have a love for each other like I have never



seen. He is heaven on earth.

Huge Step

He has been taken off his ventilator.

And he is now breathing in his own with the help of a CPAP. This is a huge step especially at only a day old! We have got a little fighter in our hands!

Fingers Crossed

He is still on CPAP and has not had to go backwards to the vent, which is incredible. His right lung needs a little extra help, so he is propped up on one side to strengthen it. They will be doing an echo on his heart to see how it is doing so fingers crossed for that one. All in all, he is doing really well.

Sunbathing

He is currently in what we call Florida. He is laying in a tanning bed for his bilirubin wearing shades; it's 98 degrees and 85 percent humidity. His

eyes are still fused so we feel like he is just using his imagination and picturing all of the babes at the beach.

Tears

Mom and dad are home which is so much harder than I anticipated. I have not really stopped crying. Nash is doing great though, which makes it a little easier. He is still breathing well on his own, his bilirubin has improved as well as his sodium levels. His nursing staff is incredible, and he is in the best hands! We are so grateful for his NICU team!



Nash Taco

He is still doing well. They have him wrapped up like a little Nash Taco today because he is feisty, and it helps him stay calm. He does have a hole in his heart, but all babies do at this gestation, so they aren't worried for now. They will be doing an ultrasound of his head to check for bleeding in his brain which has been my

biggest fear so special prayers and good vibes that he is all good there. We have a strong little dude everybody! **The Whole World**

Our sweet, perfect little man had an ultrasound done on his head yesterday to check for a brain bleed which is common in babies born this early. Unfortunately, it was confirmed that Nash does have a few bleeds. They are graded by severity with a grade 1 being the most minor and grade 4 being the most severe. Nash has a grade 2 bleed. What this means for his future is completely up to Nash. We were told he could have minor delays or severe deficits. Only time will tell. The world has never felt so heavy. As parents, all you want is to give your baby the whole world. You want life to be as happy and as easy as possible. The thought that Nash's life could be extremely challenging is devastating. Sometimes the guilt I feel of bringing him into this world to face such a hard road feels like too much. We are praying for him and loving him and that is all we can do. He is the most loved little boy on this earth.

Time for Some Good News!

The words that are being used to describe him are “remarkable” and “miraculous”. He has handled everything that has been thrown at him so far! He had a PICC line out in his belly wasn't doing the trick. It didn't tucker him out, so his oxygen dipped a little, but he recovered quickly because he is an absolute champion. He is off the bili light because his levels have stabilized so no more blue light to distort our cute pictures! They increased his feeding volume because he is tolerating it well which is great. The more calories the better! He is still on CPAP and not back in the ventilator which is just incredible and completely unexpected for his age. We have got quite the fighter. He is known as the feisty one in the NICU and we think that is just fine.

I Found Heaven

I got to hold Nash for two hours. Our nurse Jason told us that it is almost unheard of for a 24-week baby to qualify for holding this soon. We were told just last

night that it would probably be closer to a month before we could hold him. Just another example of the miracle that is Nash.



Diaper Time

Dad got to do his care routine which includes changing his diaper, checking his temperature, and cleaning his gums. He also loves to hold daddy's finger which melts my momma heart. Abe is the best dad and Nash is obsessed with him already.

Happy One Week Nash!

He is back on the bili light and some of his labs came back high/



low for one reason or another but that is going to be common through this journey. Overall, he is doing well. He has been off the ventilator for almost a week!

My two favorite boys got to snuggle today and it was magic. I love this little family of mine. These two have made all my dreams come true.



Great Day, with Exceptions

Nash is doing great today! He is still stable. Sadly, our holding privileges have been revoked.

There are certain criteria that babies are required to meet before they can be held and one of them is that they have to say over 750 grams. Nash weighs 560 grams. We were told that the order to let us hold him never should have been put in this soon. We totally understand and just want what is best for him. He is doing so well, and we don't want to rock the boat. Once he chunks up we will get to hold him all we want.

Perfect Miracles

His PICC line is coming out so he will only be on oral meds now which sounds good to me because that big IV in his tiny arm breaks my heart! He is doing remarkably well according to his team. I had four members of his nurs-

ing team stop me on my way out today to tell me how well he is doing. His nurse said when she came in this morning she had to double check his age because she was surprised that a 24 weeker was doing so well! He is our perfect little miracle, and he is showing us how much he wants to come home!

A Good Day

We were told today that where the average 24 weeker is, Nash is about two steps ahead of that. His physician said he is worth celebrating because he is doing so well!

He had another ultrasound on his brain to check in the bleeds and there has been no change, which is favorable to them getting worse. His physician said his bleed is in a place that his brain may very well be able to rewire around the damage. They truly don't know but he said he would lean toward being optimistic. Today was a very good day!

The Best Hands

Nash had a hard night, and it has continued into the day. His breathing keeps faltering which causes his heart rate to drop. They have given him an extra dose of caffeine which stimulates him and encourages him to breathe, and they have also put him on a different breathing apparatus that has a tighter seal than his nose cannula, so hopefully it will help when he holds his breath. They also added another feeding tube that goes straight to his intestines because he

isn't tolerating his feeds very well and he keeps spitting up which is contributing to his breathing issues.

We are going to see if these changes help but if they don't he will have to go back on a ventilator. It's not the end of the world if that happens. His nurse said that she thinks he is just getting tired. He has been going so strong for two weeks, so he was bound to get tired eventually. We are so proud of how well he has done so far. These are the ups and downs of the NICU that we were warned about. It's scary but he is in the best hands!

Back on the Ventilator

Nash is back on the ventilator, and he is also on an oscillator. Basically, this means that a machine is doing all the work when it comes to his breathing. Honestly we haven't seen him this relaxed in days. He is getting some much needed rest so he can continue fighting. He is doing really well otherwise. He doesn't have an infection, which is a huge relief. We got to do his cares for the first time in two days because he is no longer on the minimal stimulation protocol which means he is stable enough for us to bug him a little with cares. Side note: look at him next to a newborn diaper. His size will never stop being shocking!

Open Eyeballs!

We have got two open eyeballs everybody! This little guy was excited to see mom and dad tonight. He seems so much



more relaxed now that he is getting some good oxygen from the ventilator. He has been started on a steroid to help his lungs develop and hopefully he will be back off the vent soon. We love our little man more and more every day.



Best Friend

This guy has a best friend, and it is his paci. I don't know how he manages to suck on it with all of those tubes in his mouth, but he has got it figured out. Is there anything more adorable?

Wonderful Sign

Despite the slight setback with the vent, Nash is doing really well. He is on full feedings which his doctor said is a wonderful sign this early on. He started a steroid for his lungs so hopefully we will start seeing the benefit from that soon. He is probably going to require a blood trans-

fusion because he is slightly anemic, but we were told early on that would probably happen. He is still putting up a fight and showing us how badly he wants to go home. Our tough little guy

Great Night

Our little man had a great night, and he is coming off the oscillator today! He will just be on the ventilator which means he is making improvements. His oxygen is slowly being weaned down so that he can eventually come off the ventilator as well. So proud of our little guy!

Naps are for Babies

This little dude has decided that naps are for babies. Every time we visit, no matter what time it is, his eyes are wide open. He just wants to see the world even if it is blurry and full of indistinguishable faces and shapes. Side note: obsessed with his tiny bit of wispy hair! Now that the IV in his head for antibiotics is gone you can see more of it on top cutest little man!



Good Day, Bad Night

Nash had a good day but unfortunately he

had a bad evening. This picture was taken during his cares, and we thought he was just really relaxed but we quickly found out he wasn't feeling well. His respiratory therapist noticed that his oxygen level on his ventilator was high as well as his CO2 level, so she ordered an X-ray. The images showed that he had a pneumothorax which is when air leaks outside of the lungs and into the chest. The pressure from the air was causing his lung and his heart to shift out of place. He was probably really uncomfortable.

They had to insert a needle into his side to pull the air out of his chest. He tolerated it well and they were quickly able to wean his oxygen down which is a good sign. They did a repeat X-ray which shows that the air was successfully removed, and his lung and heart had returned to their rightful places. We asked what caused the pneumothorax and his doctor responded with "being born at 24 weeks." Unfortunately, these tiny little preemies are just prone to these kinds of issues. He seems to be on the mend, and we are so grateful for his amazing medical team that recognized that there was an issue quickly and were quick to fix it. He truly is in the best hands.

Poked and Prodded

Our poor little dude is so tired. He has been poked and prodded a lot in the last 24 hours so he is just resting for now. He is stable and the pneumothorax

seems to have resolved and has not come back.

They tried to draw some blood for a blood culture to double check for an infection, but they can't get him to bleed so they are just leaving him alone for now. His doctor said an infection is low on her list of concerns, she just wanted to double check. Mom is a basket case and dad has been our rock. It's not fun seeing your baby have a hard time but we have been assured that this is all pretty typical for a 24 weeker so none of this is unexpected. We are still hating every minute of it but we have a really tough little boy and we are so grateful for him!

Whole New Baby

We just got a call from Nash's doctor who said Nash is like a whole new baby today! He said everything has seemed to stabilize and he is doing really well. They can now focus on weaning him off the ventilator! We have such a strong little guy! He just needed a little break.

Feisty Attitude

This guy seemed to be more himself tonight. He has been really lethargic the past few days. It was obvious that he really wasn't feeling well but tonight he was a little more awake and was showing us some of that feisty attitude that we know and love. We are really hoping he is on the up and up. Hopefully we can get back to trying to wean his oxygen down and focusing on getting him off of that ventilator. He was surrounded by some familiar

faces tonight which I think helps him feel more comfortable. He loves his Nurses Shantel and Katelyn and his Respiratory Therapist/girlfriend Megan and so do we. We know he is in amazing hands.

Reverence Never Lasts Long

Nash was wide awake and as feisty as ever during his cares tonight. It's so good to see him back to his old self. He was full of energy and trying to pull all his tubes and wires off of himself which is typical for him when he is feeling good. His RT Megan always tells him to "be reverent" and she folds his arms. His reverence never lasts long, and we always have to hold his hands. I kinda think it's a ploy to get cute girls to hold his hands. He is quite the ladies' man. We love when he is all swaddled and comfy and just stares at us. He is the cutest little guy we have ever seen. I think we will keep him.

Life Outside the Womb

Just Nash thinking long and hard about if he is going to be good tonight or if he is going to have lots of Brady's (drop in heart rate) and Desats (drop in oxygen level). Just the typical micro preemie fun (not). In all seriousness, he has been really good today. He is so tough and is slowly but surely figuring out how to do this whole life-outside-the-womb thing.

Brushing Peach Fuzz

Mom got to brush my peach fuzz hair tonight while I happily

sucked away on my bink. Just living the good life.

Nash is still doing really well although doesn't seem to be ready to wean off of the ventilator. His medical team has decided to put him in a diuretic that helps with inflammation in the lungs. He is also now old enough for a steroid that should help as well. Overall, he is doing really well. We are so proud of our strong little boy.

Putting on the Weight

Nash's nurse just called and told us that he gained 50 grams! He now weighs 700 grams which is 1.5 pounds! We are some proud parents!

Dynamite in Small Packages

When I was little, my dad, Nash's late Grandpa Wilson, used to tell me that dynamite comes in small packages, and I could do anything. I am seeing now how right he was and that maybe he wasn't telling me that for me but for the tiny stick of dynamite that would be Nash.



Our Little Piece of Heaven

Not sure why he looks so concerned

because he had a really good day! Nash graduated from the High Frequency Jet Ventilator to a conventional ventilator! This is extra exciting for mom and dad because we can hold him on the conventional ventilator when he weighs enough. Tonight, he weighed 710 grams, so we are so close! Mom and dad cannot wait to hold him again!

Our own little piece of heaven

Some Kind of Bug

Nash is stable and seems to be doing really well on his new vent. They tested his endotracheal tube from his last vent, and it came back positive for some kind of bug. That isn't necessarily bad news. His doctor said that they can treat that bug with antibiotics, and it may actually have a positive impact on his lung function if that bug is what is causing him to require more oxygen. Otherwise, he is cute as ever and weighed in at a whopping 770 grams tonight which is about 1 pound 10 ounces!

Wide Awake

We had a wide-awake little Nash burrito tonight! He is doing so well and just gets cuter by the day! If he stays stable through the night and has a good day tomorrow, we will get to hold him! Our hearts can barely take it.

One Month

One perfect month of heaven with our little miracle. He has already changed so much. The biggest milestones this past month have been:
- being on NIPPV for two weeks! (He

ended up back on the vent but we still celebrate how strong he is)

- graduating from the bili light
- gaining 5 ounces since birth
- growing half an inch
- the hole in his heart closed on its own
- he successfully stole the hearts of every medical team member he has met.

Can't wait for the rest of our lives with you Nash. You are truly heaven on earth and we are so proud to call you our son.



Hard Day

Nash had a really hard day today. His endotracheal tube had an 80 percent leak because the tube was too small, so air was escaping around the tube. His doctors decided to put a bigger tube in, but they decided to let him try to breathe on his own with the help of a CPAP since they were extubating him anyway to change tubes. He was extubated for a couple of hours but then he started to struggle. They re-intubated him, and he has since somewhat stabilized, but they are trying to figure out what went wrong. If he has an infection or if he just got stressed from having to work

so hard. They are also currently concerned that he has Necrotizing Enterocolitis (NEC) which is basically an infection in the bowels and could possibly lead to surgery. We are asking for all the prayers, good vibes, whatever you believe in. This is probably the scariest thing we have faced so far.

Too Big for this World

Nash was just too big for this world. His tiny little 1 pound 5 ounce body filled the whole world with so much love for a whole month. He made us parents which is all we have ever wanted. Unfortunately, he developed an infection and we lost him really quickly.

We were both by his side, holding him when he passed. We got to give him a bath, change his diaper one last time, and put him in his first outfit. He was so beautiful and fought so hard his whole, too short, life. He made us laugh with his big, feisty personality and he gripped our hearts with those tiny hands (When he wasn't using them to try to yank out all of his tubes). Our hearts are always his. We love you Nashy. You are our little boy forever. Be at rest now. We want to thank everyone for all of their love and support.

You have kept us afloat through this journey. We are so grateful for his medical team for how hard they fought for him and for how much love they showed him. He was in the best hands.