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FAMILES LIKEUS CHILDREN & THEIR DEVELOPMENT



THE "NICU"?

CAMILLE PLANTE'S IN-DEPTH STORY OF THE NICU

FAMILIESLIKEUS.COM

FAMILIES LIKE US Letter from the Editor



WHAT EXACTLY IS A "NICU"?

n this month's edition of Families Like Us, we had the opportunity to get an exclusive, in-depth piece on the struggles families face when their children must be admitted into a neonatal intensive care unit after being born prematurely or when other issues happen during birth.

This piece was beautifully written by Las Cruces local Camille Plante, who along with her son, lived through a fragile premature birth. Read about this magnificent, moving story in this month's issue in the next page.

So, with all this talk about the importance of a neonatal intensive care unit or NICU, the question seems to pop up – What exactly is an NICU?

A NICU is an intensive care unit specializing in the care of ill or premature newborn infants.

Throughout the years, NICUs were not that common with the first one designed by Louis Gluck and opened in October 1960 in New Haven, Connecticut, according to Neonatology on the Web, an online NICU resource.

But since then NICUs have grown to be more common in communities because of the great work they provide for the community.

The two hospitals in Las Cruces, Memorial Medical Center and Mountain View Medical Center, both have NICUs that aim to help the families of Las Cruces and the surrounding areas.

That is why it is important to have people who know how to support families while they face the NICU and when they transition to the home setting.

Go to **FamiliesLikeUs.com** for more information.



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WHAT'S IN THIS EDITION:



EXCLUSIVE IN-DEPTH STORY

Camille Plante discusses her family experiences in the NICU and her duties to the community as a NICU Family Support Liaison.



DIALING DOWN EARLY INTERVENTION

From what early intervention is to what early intervention is to what healthcare professionals are doing, here are the details every parent should know about early intervention.





ABOUT US

Families Like Us is published monthly by Cheddar Advertising and is free to our readers. This publication aims to inform the Southern New Mexico public and beyond of the issues facing our communities in regards to child development. Our goal is to shed light on child development and the issues surrounding this subject.

SUBMISSION POLICY

Families Like Us is always open to collaboration that will create awareness to child development and welcomes submissions. Submission can be emailed to anthony@cheddarize.com. Families Like Us reserves the right to edit submission and cannot guarantee publication.

ADVERTISING POLICY

Space in this publication will be available soon for paid advertising.

FROM MOTHER TO ADVOCATE

NICU MOTHER BECOMES MECA THERAPIES NICU FAMILY SUPPORT LIASON

By Camille Plante

BEGINNINGS

n 2010, I married the love of my life. Dustin and I were happy and healthy, and decided we wanted to expand our household

of two. We excitedly went to the doctor to assure that I was in good health, and I was. Within no time at all, I was pregnant.

Everything was going great. I felt pretty well as the months progressed. But, without warning, on Feb. 28, 2012, we suffered what is considered a late term loss at 23 weeks and 2 days into the pregnancy. There was no explanation, no reason anyone could find...just loss.

A SECOND CHANCE

Dustin and I helped each other move forward and heal. We were given the green light to try again. After much consideration, we decided to do just that.

We conceived again and everything seemed to be right on track again. I was a little nervous when I realized we had conceived around the same time, which meant we would be on the same time line as the previous year. Maybe I was just being paranoid.

The pregnancy progressed very well, and I went to extra ultra sound appointments this time around to watch for anything out of the ordinary. The baby was a boy and developing right on schedule. We could see at 22 weeks that he had his father's nose. He was so active they had a difficult time getting measurements on him. We never got an Umbilical Doppler to record the blood flow rate through his umbilical cord because he was always playing with it.

UNFORESEEN CIRCUMSTANCES

On Feb. 27, 2013, I started having cramps that just did not feel right. I went to the hospital and was admitted. The baby was doing fine, but there was a mass that could be seen in the uterus with the baby on ultra sound. We could not be sure what it was. With cramping subsiding and baby doing well, I was sent home the following day. It was recommended that we follow up with more ultra sounds at University of New Mexico in Albuquerque the following week and that I should be on bed rest until then.

My bed rest would last 45 minutes. I had dozed off for a moment, tired from the previous day's activities. I knew something was not right when I woke. I ran to the restroom and lost about a pint of blood. Dustin rushed me to the hospital, while I quickly alerted the doctor. He set everything up for me to be admitted as I arrived.

The nurse came in after I was gowned up and laying in the bed. The first item of business was to see if baby was ok. After a fetal monitor showed a strong heart beat, they turned their attention to me.

..."There was no explanation, no reason anyone could find...just loss."

FAMILIES LIKE US Exclusive In-depth Story

I was losing a lot of blood. There was no way to stop it. They gave me a steroid shot hoping it would jumpstart the baby's lungs to develop because the truth was that the pregnancy was over.

They were quickly making arrangements to get me and the baby to El Paso, where he had a better chance of survival to be born at a hospital that had a level three NICU. They said I would most likely not survive the trip because I would bleed out. Now both mine and my unborn child's life were on the line. How did we get here?

We discovered that the transport from El Paso had not left, and it was 5 p.m., rush hour, with an hour to travel. I was so worried about my baby that I was not paying attention to what started to become clear to everyone in the room. I was bleeding to death.

It was estimated that I lost about six to seven pints of blood. I was taken for an emergency C-section. As they wheeled me back, terrible words kept pouring out of their mouths. They said they would not attempt to save my son if he was less than 500 grams in weight. They said the survival rate would be slim. They said he may be blind, and or deaf. They said he may have cerebral palsy. There were so many people in the operation room: a surgical team for me, a neonatal team for the baby, nurses to go with each team and several techs.

I felt the first incision, so they quickly knocked me out. I only have stories from now beloved nurses and doctors for what happened next.

RYDER J. PLANTE IS BORN

Ryder Jay Plante was born at 6:15 p.m. on Feb. 28, 2013. He weighed 610 grams, that's 1 lb. 6 oz. He was intubated and central lines were placed into umbilical cord. He was wrapped in cellophane and placed in a transport incubator. The transport team had arrived and was waiting for Ryder to be stable enough to travel to El Paso. We would be informed that Ryder had a less than 10 percent chance of survival. The delivery doctor told one of the nurses that Ryder would not survive the night.

I was waking up and was quickly told that my placenta had detached and as soon as baby was born they were able to stabilize me and that I was no longer bleeding. I was informed that I had a large septum in my uterus that had made this happen. I was told the mass in my uterus with



the baby was a blood clot that had been as large as the placenta. The bleeding started days earlier without us knowing.

The baby was alive; I could see him before he left.

I was taken back to my room where my husband, my mom, my dad, my aunt and my sister-in-law were waiting for me.

..."Now both mine and my unborn child's life were on the line...How did we get here?"

They rolled my son in and he looked like he was in a rocket ship. I could see him through the glass. He was wrapped in sandwich wrap and looked like something out of a movie. He didn't look like a baby. He was a fetus. He was so tiny and looked so fragile. How could this be my son?

This wasn't fair for him. He deserved a better chance. I felt like I had failed him. He was leaving. I couldn't get up. I was



heartbroken.

The next two days were the worst ever. I was in a hospital in Las Cruces, and my son was in a hospital an hour away. My husband was at his side each day and would come home with pictures and information. The fact that the little fighter had survived over 24 hours was huge. He was on life support and was watched by one nurse on one to one care. I couldn't relate to anything I was being told. None of it made sense or seemed real.

When I finally could go to him, I was in a wheel chair and still very weak. I had my little bottle of milk I had been pumping like homework to be turned in. When I was wheeled to his spot, I was overwhelmed by alarms, machines and a nurse talking to me like I was a colleague and knew this whole new language she was speaking. I blocked it all out and stared at my son.

His eyes were closed. I found out that his eyes were actually fused, like a new born puppy. He smelled like blood. He was purple, his skin was so thin. I touched his hand, even though they told me not to. He was so young and still so undeveloped: that touch could drop his heart rate quickly. His fingers felt like a whisper. I was told not to pay attention to the monitors or alarms and to only focus on my son.

Days later, Dustin and I were told to prepare for the worst. We were told that it was not looking good. That he was just too small and that God has a plan. Well, I guess there was a plan...

THE FIGHT CONTINUED

Ryder kept fighting. He opened his eyes on the 10th day. They were huge. We looked into his eyes and made a promise to be by his side every step of the way. We told our nurses to stop with the negative reports. We wanted to know about new developments, and planned procedures, and anything > else that was happening, but no more negative thoughts or comments. I began studying and looking up everything I did not know that was said to us, which was

a lot. I began to learn the language of the hospital and soon could rattle it off right back to them. It made visits and updates efficient and thorough so I could focus on my Ryder.

Ryder had many ups and downs. On several occasions, we thought we might lose him. He fought on. He battled his nurses, and they called him the Spicy Jalapeño. We had one feeding intolerance issue after another and a heck of a time getting him to gain any weight. His breathing issues were huge. Switching from one ventilator to another, testing blood gases several times a day and trying to stay ahead of damage to the lungs caused by each ventilator was making him weak and caused him to require weekly blood transfusions. I would not be able to hold him till he was 38 days old.

NICU EXPERIENCES: THE 'DEN MOM AND DAD'

As time went on in the NICU, we became very well known to the other families around us. We were a constant and became familiar to everyone. The nurses began asking us if we could speak to new parents or if they could ask us questions. I began collecting phone numbers and receiving late night and daily texts from confused and distraught parents with babies in the NICU. We became the "Den Mom and Dad" of the NICU.

We saw the best and worst of what can happen in the NICU. We cried with parents and laughed with parents. I helped them

understand NICU procedure, rules and regulations, and what could be expected as time moved forward.

The time finally came for us to start our transition out of the NICU. Ryder had to have a surgery to repair hernias, and had to be moved to regular oxygen, and I had to learn how to successfully place a nasogastric feeding tube. We had a hearing test to complete and a car seat challenge.

After 178 days, we were finally going home. It was a miracle! Ryder was 6 months old, almost 5 pounds, and we were ready to conquer the world – so we thought.

TRANSITIONING FROM THE NICU TO HOME

We were released into a world of doctors' appointments, early interventions therapies and basically turning our nursery into an at home NICU, except we had no nurses to help and no doctors rounding daily. I was still getting daily calls from

parents needing help, and I was in the trenches. There was no help. I didn't understand what all the therapists were for and why we had to start them already. I was busy trying to keep Ryder on track. We had oxygen, a pulse ox monitor, tons of meds to administer, and feeds to gavage through the feeding tube. He required a lot of care still.

So, I dug in again with learning everything I could about our situation.

I called an early intervention therapies company and set up an appointment so they could come and tell me what they wanted to start with and what I thought would work. I didn't want a rush of people coming in with a medically fragile baby. I was afraid of outside germs, I was afraid of too much happening that I was not in control of. I learned that everyone, when communicated with, was willing to help and adhere to his schedule. I learned to speak up and not be afraid to voice my needs.

As I moved forward with Ryder's therapies and appointments, the calls from other parents kept coming. I began to see a need for someone to help in our community. There is no one giving information up front. There is no one walking you through the transition from NICU to what comes after the NICU. There was not enough information being offered on each option. I saw a need, and I knew I needed to figure out a way to help, but I wasn't sure where I could start.

I knew help needed to start at birth – when it all starts.

THE MARCH OF DIMES REACHES OUT

Around the time that Ryder was a year

and a half, the March of Dimes, a nonprofit organization that works to end premature birth and other problems that threaten infants, contacted me and asked if we would consider acting as the incoming Ambassador Family to tell our story and spread the message for the need for more research. We were excited to spread our story in hopes of helping families like us. I was soon asked to join the March of Dimes board, and I was excited to serve my mission even further. They have said it helps to have a mission parent involved to bring a new perspective to the cause.

I still felt more could be happening. The Rise of the Wee Warrior Project I began to form the idea that I could supply blankets that could cover babies' incubators in the NICU. That was the first thing we were

in the NICU. That was the first thing we were unprepared for. They require darkness and something to muffle the sounds and activities of the NICU.

I also thought food that could be delivered for family's freezers would be of help. It's hard to get to the store in these situations.

So, I formed the Wee Warrior Project and am currently recording it as a non-profit organization for New Mexico families. I have begun to reach out to families within our community and am delivering information from March of Dimes with each delivery I now can make happen.

Last year, I put together and executed a Gala to fund March of Dimes' research and fund the Wee Warrior Project. We were able to donate over \$27,000 to March of Dimes, and we have made two successful blanket deliveries to each Las Cruces NICU and done many private deliveries as well. Our next Wee Warrior Gala will be Feb. 24, 2017. This is just the beginning.

NEW COMMUNITY PARTNERSHIPS

Through a new partnership with MECA Therapies, we as a team will be able to create the framework to support families like us in our community and throughout the state of New Mexico.

With my experiences both personal and through community outreach, I will join MECA Therapies to create a new position to support families in transition.

As a family liaison, I will help the therapeutic teams be prepared for each individual case so that they walk in ready to work. Each family will have a point person to help them through a very trying time.

We will also continue our work to help families with the support of the Wee Warrior Project and eventually offer support to NICUs all over the state.

MECA Therapies has made it their mission to see a better system in place for this transitional time, and I am thrilled to be a part of it.

EARLY INTERVENTION MOVING EVERY CHILD AHEAD

From what early intervention is to what healthcare professionals are doing to aid those affected.

CHILDHOOD DEVELOPMENTAL DELAYS & DISABILITIES



ach week in New Mexico, about 500 babies are born, and of these babies, all are at risk for a developmental delay or disability. Many factors contribute to a potential delay and disability, such as prenatal risks:

- chronic maternal illness,
- certain maternal infections,
- toxin exposures
- and nutritional deficiencies.

These factors can then lead to pregnancyrelated complications, which are also linked to developmental delays and disabilities – prematurity, low birth weight and infection during pregnancy or birth.

Throughout the country, infants and toddlers are affected by developmental delays and disabilities, which can have a negative impact on their long-term development.

There are huge differences between a developmental delay and a developmental disability.

A developmental disability is physical and mental. Affecting about 1 in 6 children in the U.S., children do not outgrow developmental disabilities, causing issues with learning and self-care.

For example, down syndrome, autism and brain injuries can cause developmental disabilities, and are not learning disabilities.

Developmental delays are determined by the progress of a developmental milestones during certain times.

NEW MEXICO FIT PROGRAM & EARLY INTERVENTION

Family Infant Toddler (FIT) Program serves infants and toddlers who have or are at risk for developmental delays and disabilities by providing early intervention services. The program is essentially free to families in New Mexico.

Integrating routine and early intervention strategies, NM FIT Program aid children age birth to three, and these services are performed in natural environments, such as the home or other community settings – child care, Early Head Start, etc – early intervention provides activities and strategies for families to use to promote their child's development throughout the day.

After nearly 50 years of conducted research there is evidence backed up by quantitative and qualitative evidence that early intervention increases the developmental and educational gains for the child.

According to the FIT Program and the U.S. Department of Education, early intervention improves the functioning of the family and benefits the community as a whole.

Children who receive early intervention require less special education and other habilitative services, and they progress through grade levels instead of being retained.

ELIGIBILITY OF FIT PROGRAM

There are certain eligibility requirements for a child to qualify for the FIT Program.

Children must be a resident of New Mexico and be under the age of three. Children must be referred to be able to receive FIT Program services – A concern about a child's development is enough to generate a referral.

A diagnosis or delay is not necessary to generate a referral – The FIT Program will conduct a free developmental screening to determine the child's eligibility based on one or more of the following criteria:

- Developmental Delay
- Established Medical Condition
- Medical/Biological Risk
- Environmental Risk

EARLY INTERVENTION **BENEFITS**

98%

98% of children enrolled in FIT primarily receive early intervention services in the setting where they typically live, learn, and play – in order to ensure that the activates become a part of their, and their families', typical routine.



95%

99%

99% of children enrolled in Fit had improved in their positive social-emotional skills (including social relationships) whey they exited the program.

95% of families surveyed report that early intervention services have helped them help their children develop and learn.

99% of children enrolled in FIT had improved in their use of appropriate behaviors to meet their needs when they exited the program.



99% of children enrolled in FIT had improved in their acquisition and use of knowledge and skills (including early language/communication when they exited the program.



92% of families surveyed report that early intervention services have helped them communicate their children's needs effectively.

> Source of Stats: New Mexico Family Infant Toddler Program & New Mexico Department of Health.





^{lank} you for helping babie

MECA Therapies would like to welcome Camille Plante to the team as the NICU Family Support Liaison. We look forward to impacting this community with the help of Camille and her work with NICU Family Support.

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