

American Preemie Foundation



A quarterly newsletter for families of preemies

Preemie News

April 2009 Volume 1, Issue 2



Did you know...

Almost all babies lose weight after birth before they begin to gain weight. This weight loss typically is 5-15% of the baby's birth weight.

Source: www.meriter.com

Welcome to American Preemie Foundation

The American Preemie Foundation was founded in 2008 to help families currently caring for preemies in the hospital.

It's hard enough to have a child in the hospital, but it's especially difficult when that child has been there from the moment it was born and could spend several months under the care of the hospital staff.

The American Preemie Foundation was formed to

help families that are overwhelmed with the expenses that are associated with having a baby in the hospital for so long. If a family is lucky enough to have health insurance, the medical bills are generally taken care of, but what about the grocery bills, lodging expenses, and gas to and from the hospital?

That's where the American Preemie Foundation comes in. We're here to help where we can and provide a

stress free environment for preemies and their families.

When a preemie is in the hospital, the last thing a family needs to worry about is how they are going to pay the bills. Parents need to focus all of their attention on their baby.

Through generous donations from you, we can all come together to help these families and their preemies.

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Preemie Health – RDS

Each newsletter highlights a medical condition common to preemies. This quarter, we highlight Respiratory Distress Syndrome (RDS).

RDS is the most common lung disease of preemies and occurs when your baby's lungs don't fully develop. The more premature your baby is, the higher the risk of RDS.

Symptoms of RDS in your preemie include rapid breathing, pulling in of the

chest region during breaths, a grunting sound during each breath, and widening of the nostrils during each breath.

Treatment of RDS can include increased oxygen, CPAP, or breathing tubes depending on the severity.

Recovery from RDS is dependent on factors such as birth weight, severity of RDS, infections, and other illnesses. Recovery could take one to six weeks.

Long term problems could arise from RDS if your baby's case was severe or if there were other complications. During the early childhood years, your child may get severe colds, may have a higher chance of asthma-like problems, may be hospitalized more frequently, and may have scarring of the lungs which is called Bronchopulmonary Dysplasia

Spotlight on Preemies

We asked you to submit stories of your tiny miracles and we received an overwhelming amount of responses! Thanks so much for your support.

Since we received so many stories, we will be sharing them throughout the year. So if you don't see your story here, it will be included in a future newsletter or may have been in our last newsletter.

We are including your stories in their entirety since we didn't think it would be fair for us to edit your experiences to save space. But we have edited for spelling (as best as we could).

The American Premie Foundation is convinced that sharing stories is crucial to building support for the premie community as a whole. It is a way for you to read about others and

realize that you are not alone.

Please feel free to share with us more stories that you have and updates on your preemies. You can submit them to contact@preemiefoundation.org

Thanks again for your support and your wonderful stories. We hope you enjoy them!

Jaxon



My son, Jaxon, was born May 2, 2008 at 29 weeks 2 days after a completely uneventful pregnancy until week 28 when I started having contractions and hemorrhaging. He was delivered via emergency c-section as he was breech and I was dilated to a 5. At birth, he was great! He weighed 2 lbs, 11 oz, scored a 7 and 9 on his Apgar and was breathing on room air. All of his scans were normal, except for his PDA which closed after one round with Indocin.

His feedings were going well until day 10 of his life, May 12th, when he developed NEC. In a matter of hours he went from room air to the oscillator ventilator. His skin was dusky, he was extremely lethargic and he looked as though Death himself had taken him. He became hypovolemic and required numerous infusions of blood products (FFP, RBC's, platelets) and Dopamine in an attempt to stabilize his blood pressure which was dangerously low. He fought hard all night but in the morning, his neonatologist decided the level III NICU in Modesto, CA where he was born was no longer sufficient to support his needs as he was now in severe septic shock. On May 13th he was transferred to Stanford via helicopter. For the next week Jax fought hard for his life. He was in virtual systemic organ failure, including renal failure, respiratory failure, etc. The third spacing and round the clock blood products had nearly tripled the size of his 3 lb body and his skin was a deep purple. The immense third spacing caused too much pressure on his lungs, causing his right lung to collapse. He no longer looked anything like the healthy son I had delivered only a few weeks prior. The NNP's and doctors have all confided in me since that they did not believe he would survive his first night at Lucile Packard, let alone through the week. In fact, when we first arrived, the first thing the NNP said to us was, "Your son is one of the sickest babies we have seen in a LONG time...even for Stanford."

However, after taking his life hour to hour, after about a week, Jaxon began healing and he weened himself off the pressers, off the Dopamine, off the ventilator and began shedding the extreme swelling he had taken on. In essence, he began looking like a regular baby again. Once he began

healing, the x-rays revealed what they had been unable to see before but had suspected; Jax's intestines had been perforated through from the bacteria that had made him sick.

About a month after getting sick, Jax had to undergo a bowel resection due to strictures/scarring in his bowel from NEC. They removed about 20 cm total from his small and large bowel, including his ileocecal valve and his appendix (which they said was a "bonus" so we wouldn't have to worry about future appendicitis). The surgery went well but his post op forced him once again to fight for his life. His systemic response mimicked his reaction to NEC. He became once again hypovolemic, was forced back on the oscillator and required countless transfusions and large amounts of Dopamine to maintain his critically low blood pressure. He also severely third spaced and blew up in size again, causing more collapsed lungs. His incision also became infected with pseudomonas, a potentially lethal bacteria. However, after about a week, he started to pull through. What we were unaware of going into surgery was that his adrenals had taken a hit during his bout with NEC, causing them to be insufficient going into surgery, which is why he once again had difficulty maintaining his blood pressure.

After a long recovery, including a fungal infection from having been on so many antibiotics, Jax was finally able to eat after 11 weeks without food. He was able to tolerate full feeds and he did it all without the need for an NG tube. We were sent down to the intermediate care nursery and were prepping to go home when he got NEC AGAIN on August 1st. This time, however, he was completely stable in his vitals. However, his belly was distended and he had bloody stools. Upon CT of his bowel, they discovered MORE strictures and once again he had to have another bowel resection. This time they took about 5 cm of bowel. This recovery was a little easier on him. His right lung did collapse again due to more third spacing and he did require the use of a conventional vent but he did not need the oscillator or the use of pressers to maintain his blood pressure. He also grew out pseudomonas again from his wound. However, while healing, his surgical wound dehiscd (it opened up) and they had to take him to surgery again to repair it. After surgery, one of the intestine sites they had put back together, perforated, and he required the use of a peritoneal drain to eliminate the toxins that were leaking into his body. Again, however, he remained stable as his body globbed scar tissue over the perforated site, saving his life.

As if he hadn't been traumatized enough, he required a FOURTH surgery after another CT scan showed strictures again in the sites they had previously anastomosed. This time, however, they corrected the site in his colon and pulled out the strictured site from his small intestine into an ileostomy. This fourth post op recovery was the easiest of all of them but still included a collapsed lung and blood products, although his blood pressure was stable on his own.

After his surgery, Jax was able to eat again after he had gone 9 weeks from the last time he had eaten. During all that time, and all but one week of his entire life, he was nourished through IV medications called TPN. While TPN is necessary in order to properly nourish babies, it is very difficult for the liver to metabolize. Thus, he now has cholestasis of the liver (damage that will hopefully reverse on its own). His skin was previously a deep yellow and the scleras of his eyes were practically green. However, since we have now been off of the TPN for about a month and up to full feeds, his skin is now almost normal and his scleras have only a tinge of yellow remaining!

After 186 days we were finally released from the NICU at Stanford. At home we care for his central line (Broviac) still because he came home on still on TPN and Lipids! However, we got the okay from the GI docs yesterday to get the line removed because he has been doing an excellent job at gaining weight and eating!!! That will be one less port for infection!

His intestines will be put back together sometime in the Spring after they have had time to heal and RSV season is over. In the meanwhile, Jax is doing great and is surprisingly appropriate for his adjusted age (5 mos). He is sitting up by himself, extremely social and just so darn cute! To say he is a "fighter" is an understatement. Not only has he had to fight more in his 7 months of life than most of us in all of our lives but he has done it without it having affected his personality.

In all, in Jax's 7 months of life, he has had NEC twice, hypovolemia twice, two rounds with the oscillator ventilator, seven intubations, six collapsed lungs, one fungal infection, three bacterial infections, one UTI, three pseudomonas wound infections, three bowel resections, one dehiscence repair due to his incisional wound opening, one peritoneal drain, two intestinal perforations, an ileostomy, two PICC lines, one Broviac, kidney reflux, PDA repair with Indocin, a brain hemorrhage, two abdominal hernias (one repair thus far), an umbilical hernia repair, one emergency helicopter transfer, two ambulance transfers, one septic shock and one more surgery to go (hopefully the last).

Looking at him and interacting with him one would never know what he is gone through. He is always so mellow and happy. Jaxon is TRULY a miracle preemie.

We have a website for him at caringbridge.org/visit/jaxonroscoe

Owen

I had a very normal pregnancy until the 5th day of my 24th week. I started leaking fluid, went to the hospital, got checked for labor and was sent home when no contractions registered and tests indicated the fluid was not amniotic.

Unfortunately, several hours later, I began very heavy, very quick contractions. It happened very fast. I went from completely normal to contractions just a couple of minutes apart in a very short period of time. We rushed to the hospital and I was sure that my baby would die. I had no idea such early preemies could survive.

After my doctor examined me, he told us that I was completely dilated and effaced and nothing could be done to stop my labor. He then told my husband that he was going to call the NICU at our local children's hospital. I naively asked "why" and that's when I first realized that my son had a chance of survival.

Shortly thereafter, a neonatologist arrived with a transport team and what is called locally, the baby buggy, a mobile intensive care ambulance. The neonatologist informed us that our son had a 50% chance of survival. If he did survive, he would have a 1/3 chance of being severely handicapped, a 1/3 chance of being mild to moderately handicapped, and a 1/3 chance of being normal.

Less than a half hour later, our son was born. He weighed 1 lb 12 oz and measured 12 in long. The birth was eerily

quiet since he was too small to be able to cry after delivery. Unlike the birth of my older son, there was no happiness or joy in the delivery room, just fear. The doctor struggled to intubate him, but finally was able to after several tries. A priest was called in to baptize our little boy, we were allowed a minute to see him and then he was whisked away to the NICU of our children's hospital.

It took us several days to decide (we thought we still had months to come up with a name), but, eventually, we named our little boy Owen.

Owen spent 111 days in Kosair Children's Hospital. The first months were especially difficult. Actually, they were pretty horrible. He was on a ventilator for two months, was septic, had a grade II brain bleed, required PDA surgery, had multiple lung collapses, required many blood and platelet transfusions, a mild bout with NEC and ROP, and the list goes on and on. For every step forward, there seemed to be at least two back. There were many times that I thought Owen would not survive.

Slowly, Owen improved. Once he was off the ventilator, we were actually able to begin holding him and he slowly put on weight and became what the nurses referred to as a "feeder and grower".

He was released from the hospital on May 13, 2005, five days after his original due date.

Owen is now nearly four years old. He is a happy, healthy little boy. He spent several years in speech, occupational, and developmental therapies to help him overcome some of the common complications of premature birth. Now, he runs and plays and keeps up with other kids his age. There are times when I look at him and it takes my breath away. I just cannot believe how far he has come from the sick little baby we weren't sure would survive the ambulance ride from one hospital to the next. We have truly been blessed.

Dalila

Dalila Liron Jaime
 Due: March 13, 2008
 Born: November 18, 2007
 Gestation: 23weeks 3days
 Weight/Height: 1lb10oz, 12.5in

She was in the hospital for 102 days....came home on Feb. 28, 2008 weighing 8lbs! She was born with RDS, developed BPD, had stage 2 ROP, 6 blood transfusions, several infections, collapsed lungs, pneumonia. However we were very lucky with her....she had no IVHs (a fact I've now heard from several doctors is pretty rare in a 23weeker), her RDS and BPD were not so bad or chronic....she was actually off of oxygen several weeks before coming home. She is now a thriving 13 month old - she has no developmental delays or health problems whatsoever. Her doctors and several therapists all agree that she's pretty much caught up and where she should be. :)

Da'zon



Well, My name is Nicole Burns. I was almost 32 weeks pregnant. I began to get really sick. I just thought I had the flu. I would sleep constantly, throw up, and was so weak. I just felt so dizzy. Every part of my body was really swollen, but especially my feet. My little toes would hurt when I walked. I could wear nothing, but flip flops. Thank goodness it was in May so it was not too cold. I went to the doctor when I was 34 weeks. They checked my blood pressure. It was

around 180/110. So. They told me to go straight into the hospital. I had to wait and get registered because I never did it yet. I finally got into the room, got my blood drawn, got all hooked up, and gave a BP pill. All night, my blood pressure was still up. They started me on magnesium through an IV. The doctor walks in a couple minutes later and gives me a decision. I can either have a C-Section right now or be induced and said I would probably need a C-Section any ways. He told me my blood pressure was at 220/120. He said any longer I will have a seizure and my baby would have a stroke and he didn't know if we would make it, especially my baby. Keep in mind. This was my first time in the hospital, first IV, first epidural, and first surgery. I was scared out my mind. I said I will just get the C-Section. They gave me the papers and I signed right away. They gave me an epidural and I was on my way to the surgery room. I just layed there on the surgery bed with a iv on one side, a blood pressure machine on the other, oxygen in my nose, a sheet over me, a bright light in my face, and my baby daddy. With in minutes, my little boy was out. He was 6 weeks earlier weighing in at 5lbs 3.4 ounces, 18 3/4 inches long, and born at 2:47PM. He was such a miracle. He was very strong. He was taken to the NICU where he was all hooked up. Had an IV with antibiotics, thing on his foot monitoring his heart rate, those suction things all over his stomach, oxygen in his nose, and under the blue light. He was so brave. At first they told me he wouldn't be able to come home till his due date. Well. I was so happy. Two weeks later, we got to bring him home. He didn't have to go to his due date. He was born May 23rd, 2008 and wasn't suppose to be born till July 3rd, 2008. He sure was a trooper. He is now 7 months. At his 6 months appointment, he was 17 pounds and 3 ounces and 28 inches long. He is doing so well now. I am so proud of my baby boy and my darling baby daddy being there the whole way, even since the day we found out I was pregnant. He never missed an appointment and held my hand the whole way through the hospital. I had a bad recovery and was in the hospital for 2 weeks as well. My whole has grown so much closer through all the hard times. I am so happy we are all together this day and wouldn't change it for nothing.

Thanks for sharing your stories!

Keep reading below for more articles...

Search or Shop Online and You'll Help Preemies

How many of us use the popular search engines like Google? All of us, right? If you use search engines like Google, nobody benefits from your searches (okay, you may benefit, but hear me out).

If you go to www.goodsearch.com and make searches, American Preemie Foundation will receive a donation for every search you make.

All you have to do is type American Preemie Foundation into the box that says "Who Do You

GoodSearch For". Then you search the net. That's all you have to do. It doesn't cost you a penny, but for every search you make, Good Search will donate a penny to American Preemie Foundation. A penny doesn't sound like much, but they do add up!

If you shop online, go to www.goodshop.com, type American Preemie Foundation into the "Who Do You Support" box, and shop away. A portion of your purchase price will be donated to American

Preemie Foundation.

Again, by using Good Search and Good Shop, you will be helping the American Preemie Foundation without any cost to you.

Thanks for your support!

We Need Your Support!

The American Preemie Foundation is falling drastically short of our fundraising goal for 2009. I know we are all having a tough time financially, but now is the critical time that families with preemies really need your support.

We have had to turn families away who asked for our help. It's heartbreaking to tell a family that we can't help them.

The American Preemie Foundation does not receive any government funding, nor do we receive funding

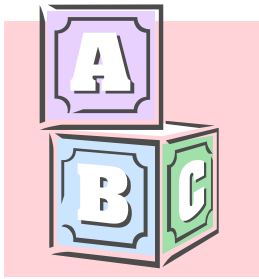
from any other organization. We rely solely on the generosity of donations from you.

The American Preemie Foundation is a 501(c)(3) organization, so any donations made to us are fully tax deductible.

Please find it in your hearts to help other families who are in the same situation as you were, but may not have the funds available to meet their daily needs.

Please visit www.preemiefoundation.org to make a donation today.

Thank You!



Volunteers Needed

Calling all volunteers!

We still need your help. If you'd like to volunteer your time for the American Premie Foundation, please contact us at contact@preemiefoundation.org

We need people to submit articles for the newsletter.

If you or someone you know lives in the South Florida area, we need volunteers to help organize events.

And we always need volunteers to help spread the word of this great cause.

Thanks!

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Extras:

If you live in the South Florida area, come join our Yahoo Group. It's called South_Florida_Premies and is a group for local families with preemies to chat. See our website for a link to join!

Check out our blog at www.preemiefoundation.blogspot.com
It's a journey through the creation of the American Premie Foundation and the behind-the-scenes boring stuff that goes on when forming a charity.

This newsletter is for informational purposes only and does not offer medical advice. Please see a doctor if your child has any medical issues.