

Preemies Today



Families Helping Families

PREEMIE OF THE MONTH:

This month we are featuring Nathaniel Kipers as our Preemie of the Month. To say that Nathaniel is a sweet, outgoing, and energetic 5 year old would be an understatement. Here is his story, as told by mom, Julie.

I planned on having a holiday baby since Nathaniel was due on the 4th of July in 2000. But, I didn't know he'd arrive on another holiday altogether – St. Patrick's Day! I had been in for my 24 week checkup and although I'd felt very tired everything seemed okay. I went on a business trip to Richmond when I started having some slight bleeding. I came back on Tuesday night and went into the doctor's Wednesday morning. I thought I would be told to go on bed rest – much to my surprise they said I needed to go to Fairfax Hospital – by ambulance – because I was five centimeters dilated already! This was due to an incompetent cervix and I hadn't realized I was dilating at all. I made it through two days of bed rest but Nathaniel's umbilical cord dropped dangerously low so I had an emergency C-section.

Nathaniel arrived at 1 pound 12 ounces and was 12 inches long. Amazingly, he had enough strength to utter a cry when he was born. This was the start of 4 months in the NICU and two surgeries for hernia complications (one was related to his colon not receiving any blood supply). Nathaniel did not have any one critical problem – but he had several serious one related to respiration, stomach infections, hernias, reflux, and vision. It seemed like when one problem cleared up another started causing problems.

Nathaniel came home at 7 pounds with a breathing monitor. It was a long round of visits to specialists every few days to monitor his progress. He narrowly missed needing laser surgery on his eyes. Nathaniel did have one additional hernia surgery at age 1 that finally solved that issue. Reflux was one of the ongoing medical issues for Nathaniel.

Although he was able to eat and gain weight, a good night's sleep was difficult to achieve. Due to the reflux Nathaniel didn't sleep through the night until age three. Sleeping partially sitting up was the only thing that prevented the reflux but like anyone, he would



shift in his sleep to other positions. He still isn't a long sleeper but we'll take 8 hours anytime. At age 5, the reflux only kicks in when Nathaniel has a cold so it's very manageable.

We used every opportunity we could to provide therapy for Nathaniel. We began using the Fairfax County early intervention services within a month of Nathaniel's homecoming. The type of therapy changed over the years. First it was occupational therapy only, at some points it was occupational, physical and speech therapy. We've worked to conquer low muscle tone and sensory integration issues. It took him a while to meet milestones but once he did he caught on quickly. He walked at 21 months (17 adjusted) and did not start saying more than one or two words until he was 3. Now he talks nonstop, so no

more quiet hours for us!

At age 3, Nathaniel transitioned to a developmental preschool in an elementary school setting. He thought riding the bus was great fun but I have to admit I was nervous putting him on the bus. (I admit I cried!) Having the small classes and the opportunity to see a new environment was great for him. The daycare I used was also great about working with me and making sure he was with kids at his same developmental level as well as having good role models. Nathaniel has just finished his second year in the developmental program and is going to kindergarten next year. Based on testing he'll only need minimal help with motor skills. It's been hard to tell what developmental issues are related to prematurity and which are related to just being Nathaniel but the therapy has helped no matter what the reason.

Although the majority of people can't discern any developmental problems with Nathaniel at his fifth birthday we are still keeping up with some therapy. Throughout the years we have met people; family members, strangers, friends, who asked why we were still "worrying" about his development or thought we were being hypersensitive. As premature children get older it's not always so obvious what issues are going on and not everyone wants to hear the long story. So, we have our short upbeat message for some, and the long-winded story for other premature parents or people who are interested in all the twists and turns that come with premature parenthood.

I am most amazed by Nathaniel's pleasant nature and affinity toward adults, especially teachers and doctors. I think he realized early on that all of the people we've met have been there to help him. I definitely appreciate every milestone he achieves. In fact I'm sure a few people think I'm crazy when I say how glad I am he is jumping on my bed singing silly songs at the top of his lungs!

Focus of the Month:

Most preemie parents quickly become experts on the various medical issues related to prematurity. However, having a preemie also means you will be learning a lot about insurance and paperwork. Although each parent will need to work with their own insurance company to determine available coverage, we have gathered some tips from parents who have had gained experience while working out insurance payments. The common theme: keep track of the paperwork and always call if you have questions!

You would think that parents of preemies would get a break when bringing home their baby from the hospital – it's not always so! In addition to the medicines, the equipment, the doctor appointments, and oh yeah, the regular baby stuff, you realize you are in the middle of an insurance fight. Just because the hospital is listed as a participating provider in your plan, doesn't mean that all sections of the hospital are automatically covered under it. Like most preemie parents, you didn't exactly have time to discuss this upon check-in, right? Right. We've been there.

So begins the many phone calls to the insurance company, the various contracted providers that treated you and/or your child in the hospital. And then the dread of seeing what large medical bills showed up in today's mail. Sound familiar?

So what's a preemie parent to do?

Plenty. While the road to getting all of this resolved has the potential to be long and frustrating and often feel like a second job, you do have rights and you do have people on your side despite what you might at first think.

Here are some quick tips to getting through the confusion:

Breathe In, Breathe Out. Repeat!

Take a deep breath and realize that you are not alone and that you will get through this. Some cases can take up to a year to be totally resolved. Just take it one step at a time.

How to Cope with Insurance Issues

Get Organized

First off, invest in a simple school notebook so you can keep notes on everything as it progresses. Second, get a large envelope or a set of manila folders so you can divide up the insurance Explanation of Benefits by provider and organize from there. Third, in the inside front cover of the notebook, write up a list of the various providers, their phone numbers, their addresses, and their office hours. Fourth, make copies of your and your child's insurance cards. Doing all of this can save you a lot of time and aggravation.

Professionalism and Making a Friend Here and There

You are going to be getting to know a few people during this process – your providers (the people you and/or your insurance company owe money to), the insurance company (the customer service team to the appeals team). The providers are your friends, believe it or not. They want to make sure their company gets that big check so chances are that they have not only been through this before with other patients but also they may have some sort of template appeals letter they can provide to you. At the very least you will get to know them and they will get to know you. All conversations with the provider should be polite and professional. Make sure that as you update your notebook with notes on conversations with the insurance company, etc. that you are doing the same by updating the provider in question. That way you become less of an account number and more of a human being.

The insurance company on the other hand, will do its best to confuse the life out of you. Every time you call into the customer service department, be prepared to wait on hold for a bit (if you have a speakerphone at home or work, use it!) Use this time to prepare your set of questions, collect all documents necessary to the subject at hand, etc. That way when you do talk to a representative, you are ready to go. If you are calling to question the way a claim was handled, simply ask them to go over the claim in detail with you. After all you are the customer, they should be telling you what they did and not vice versa.

Take Notes

This is very important. Take notes on each and every phone call and make sure to include the date, time and the person you spoke to (ask for full name and be clear you need a correct spelling of the name). That is where your notebook comes in real handy. That way all notes stay in one place and you have a chronological log of all discussions. What this will do is help you work through the confusion of the insurance company. Yes, they want you to get confused and to just give up. That is what they are hoping for. Don't give up!

Persistence Pays Off

You have the right to challenge a denied claim, so if a simple phone call to the insurance company won't work then move onto writing an appeal letter. Again these letters may already be on hand through your doctor's office. Give them a call to check and see if they could assist you with the letter. Along with the letter itself, make sure to reference any and all claim numbers and to also provide copies of the Explanation of Benefits for each claim. This is key as the insurance person researching and making a decision on this matter has all the information in front of him/her. When mailing the letter, take a simple but important step of sending the letter certified with return receipt so that you can make sure that the insurance company got the letter. Within a few weeks you should receive a letter of receipt from the insurance company itself, giving you a timeframe in which you will receive a response. Hold onto that letter and contact them once the deadline has passed. If you do not get a letter and/or you do not get a response whatsoever, call the insurance company and ask for a status.

Once you have received one appeal, you do not have to stop there. You can do another appeal but you must do so in the time limit the insurance company gives you (yes, note that the insurance company can just totally ignore their deadline to you but if you don't appeal to them in the timeframe expected then that's your problem – great customer service, huh?). If that doesn't work, then appeal to your state's insurance regulatory commission. You can

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Local News:

Preemies Today Elections

Preemies Today will be holding elections for new board members on August 21st. The election will take place during our August family event at Lake Accotink Park. There are seven available positions. All board nominations must be received by August 1st. You may submit your nominations to Deborah Leaf at Deborah_Leaf@yahoo.com.

July Family Outing

Please join us for a potluck picnic at 4:30 p.m. on Saturday, July 16 at Burke Lake Park. We will be meeting at the picnic area near the train and carousel area. RSVP to Mary Beth at marybethhazलगrove@yahoo.com.

Susan Torres Fund

On Wednesday, June 29th, at Chevy's restaurant in Falls Church, Preemies Today held a fundraiser to support the Susan Torres Fund. Preemies Today is pleased to announce that we raised over \$700 to help the Torres family. Susan Torres is a 26 year old woman from Alexandria, Virginia who collapsed of a brain hemorrhage. She was rushed to the Virginia Hospital Center in Arlington, where she has been diagnosed with stage four melanoma and is brain dead with no hope of recovery. Doctors are fighting to keep her alive through artificial respiration and other means until sometime in July to give her baby a fighting chance at life. The baby will be approximately 25 weeks gestation at birth. It is costing the family around \$1500 a day to keep her alive after insurance. You can find out more about

her story by going to her website: <http://www.susantorresfund.org>

Support Resources:

"A Friend to Talk to"

Please call us on our "Friend to Talk to" support line and one of our preemie parent volunteers can offer you some much needed support. The support line telephone number is 703-994-6624.

NICU Support Group

INOVA Healthsource offers a NICU Support group for current INOVA/Fairfax NICU families. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN. For more information contact INOVA Healthsource at 703-204-3366.

Preemies Today Online Chat

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at jkipers@lmi.org.

Local Support Groups

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information contact us at preemiestoday@yahoo.com

Preemies Today Playgroups

Preemies Today continues to offer monthly playgroups. Monthly playgroups offer our children a stress-free environment to play. Playgroups typically meet in a member's home or in a location of the group's choice. For more information contact Deborah at Deborah_Leaf@yahoo.com

Helpful Resources:

The following are some helpful resources available by phone and online:

Prince William County Social Services:

www.co.prince-william.va.us/csb/program-sandservices/

Fairfax County Department of Family Services:

(703) 324-7500

www.co.fairfax.va.us/services/dfs/

Social Security Administration:

1-800-772-1213

www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100

www.sidsma.org

March of Dimes

1-800-326-BABY

(703) 425-BABY (Metro DC)

www.marchofdimes.com

Sidelines National Support

1-888-447-4754

www.sidelines.org

Early Intervention/ Infant Toddler Connection

Fairfax County- (703) 246-7121

Alexandria- (703) 838-5060

Prince William- (703) 792-7879

Calvert County- (410) 535-1955

WIC

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

For a list of online resources please go to:

www.PreemiesToday.com

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locate your state's regulatory commission at: <http://www.naic.org/index.htm>

If none of this works, you do have the right to retain a lawyer and go after the insurance company legally. You can find a lawyer through this web site: www.findlaw.com. Always make sure to check out the firm you work with by asking for references, etc.

If you experience a particularly nasty fight, make sure that the benefits person at you or your spouse's company (whomever the insurance is under) is aware of the situation at hand. There is no better way to make your concerns known than in the form of a complaint from a benefits manager at a healthcare policy renewal meeting.

Mission of Preemies Today:

The birth of a premature infant is an extremely frightening and life altering time. Preemies Today strives to form a network of families to offer help, comfort, and understanding to one another through their knowledge and personal experience.

Membership/Subscription

Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie play-groups, and “A Friend to Talk To”, our call-in line for parents and families of preemies.

To subscribe to the newsletter please contact us at (703) 944-6624. If you would like to become a member of Premies Today please contact Mary at mlundregan@strategicm.com or call (703) 535-1421. Our website is **www.PremiesToday.com**

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