

PREEMIES TODAY

Families Helping Families

PREEMIE OF THE MONTH:

This month's preemie is Alexander Rian Arthur. Alexander's mom, Suzanne, is an artist and certainly considers him her best work! Here is his story in his mom's words.

It's not his beautiful blue eyes or his captivating smile that would give you any clues. But if you looked at his hands very, very closely they would reveal to you tiny little scars that are like constellations documenting almost every intravenous line he received during his 149-day stay in the INOVA Fairfax NICU. Today, our son Alexander Rian Arthur weighs a colossal 18 pounds and measures 28 inches long. He is crawling and pulling himself up on all our furniture and acting very much like any 1 year old; except he really isn't because he is 3.5 months premature.

This was my first pregnancy, my first baby, my first preemie, my first everything. Early on there were signs that something may not be right. I tested positive on the A.F.P. test with a 1-in-121 chance of having a child with Down Syndrome. I was asked if I believed in abortion. Shocked, I answered "No". I could not terminate a life that had been created out of love with my husband. So I did my research and found that the A.F.P. test has a very high rate of false positives. Something deep down inside of me told me that the son I was carrying was fine. So I believed. No matter what anyone would tell me about his chances, I still believed he would turn out just fine. An amniocentesis would later confirm what I had always suspected; that Alexander was genetically "normal". But because he had fallen off the growth charts we were still not off the hook.

Alexander was born just one year ago at 26 weeks weighing only 1 pound 2 ounces.

His birth marked the end to my two week long hospitalized bed rest. The cause of our confinement was a previously unknown blood disorder I have called MTHFR, which caused blood clots in my placenta and interfered with his

nutrition. On June 27th 2006 I was told that if I waited another day to have my baby that they could not promise me that he would be alive the next morning. Alexander was born that same afternoon at 3:10 via C-section.

Alexander came into this world with all the odds stacked against him because of his size and his gestation. Our son's greatest challenge in the NICU was his struggle to overcome his BPD. He was intubated from the moment he was born and remained on a ventilator for 8 long weeks. I know exactly how long he was on the ventilator because it wasn't until he came off of it that I got to hold him for the first time or even hear him cry. He was then weaned very slowly to the CPAP, next the hi-flow nasal canula and ultimately the unblended oxygen he came home on.



Although the odds were great, we were blessed with many miracles. Alexander's PDA closed on its own during his first few weeks of life. He never developed any brain bleeds and had no problems taking nourishment and growing. His stage 2 ROP completely reversed itself and the bilateral inguinal hernias he developed were repaired and are now a thing of the past.

Alexander continues to do well and is exceeding everyone's expectations. He is developmentally right on target showing no signs of Cerebral Palsy and is now completely off his oxygen. But it is funny the things that stay with you once you have been through the NICU experience. I will never forget what it felt like to walk down the long hallway to his room in the NICU wondering with each step (and baited breath) what news might await us that day. I would call to check in on him with every change of shift, superstitiously believing that if I ever deviated from my routine that it might invite tragedy into our lives. I prayed for his nurses to fall in love with him so that they would feel more personally invested in his outcome, and my prayers were answered. At one point Alexander had not one but 7 primary nurses bidding over who would have him on their shifts. My hus-

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Mission of Preemies Today:

Preemies Today is a 501(c)(3) nonprofit organization whose mission is to reach out and provide support to families of infants born prematurely beginning at birth and throughout childhood.

Vision: *We will reduce the stress of caring for a child born prematurely by creating a network of families who offer help, comfort, and understanding to one another.*

Values: *We strive to promote compassion, inclusiveness, understanding and patience.*

What We Do

We offer local in-person support to families of preemies in the extended Washington DC metropolitan area. We provide on-line support to families of preemies located across the country and internationally. Preemies Today is made up mostly of parents of children born prematurely. We network with other parents groups, healthcare providers, therapists, and people providing community resources to obtain information for our members.

Our Programs

Monthly Newsletter

Parent support groups

Online Chats

Preemie Play groups

Family Outings

Preemie Care Packages for NICU families

“Take a Break” program for families in need

“Friend to Talk To” support hotline

Resource Brochures

Online Yahoo group

Do you need

A FRIEND TO TALK TO?



If you are stressed or have questions only
another preemie parent can answer, call us at
1-888-712-3208

The Basics of Behavior

Understanding Challenging Behaviors

Running, climbing, screaming, dumping.....oh my! At times, children can display a variety of behaviors that prove difficult and challenging to manage, especially for a parent or caregiver who is immersed in the situation. The information included is intended to provide insight into understanding challenging behaviors.

Behaviors can be defined as the actions or reactions of a person in response to external or internal stimuli. These behaviors may include aggression to others or property, noncompliance, tantrums, difficulty interacting with others, as well as avoiding tasks or demands. In order to be able to change these behaviors, it is important to begin to understand the challenging behavior. There are several factors that are important to keep in mind.

All behavior is communicative and most likely purposeful. Challenging behaviors represent the child's most successful strategy to achieve some purpose. That is, the child is demonstrating certain behaviors in order to meet some kind of need. It is often the adult's "job" to identify what the child is trying to "tell" us with their behavior. When a child demonstrates a particular behavior, that behavior is serving a function for that child. The function of a behavior refers to the reason or purpose why a child behaves a certain way in certain situations. It is unlikely that a child is acting out just to get their parents mad, or just trying to be difficult.

There are different functions that challenging behaviors serve for children. There are behaviors that are emitted to avoid or escape undesired outcomes, as well as those that are emitted to gain access to desired outcomes. A child, who seeks attention by screaming or throwing toys, may not be receiving adequate positive attention during the day. The adult's response with yelling at the child can be just as reinforcing to the child as the positive attention, increasing the likelihood that the screaming will continue. A child may throw himself down on the floor because he was served an undesirable vegetable and is reinforced for this avoidance when that item is removed from his plate. Being able to recognize the functions of behavior will help in creating a plan to deal with the challenging behavior.

Dealing with Challenging Behaviors

When dealing with challenging behaviors it is necessary to observe and identify the behavior and determine its function. There are three components to look at, including what happened before the behavior occurred (antecedent), the actual behavior that occurred, and then what happened after the behavior occurred (consequence). Looking at these three factors should give more information and help us understand

the patterns of a child's behavior.

Ask yourself questions about the behavior. These questions are important in looking at the function of the behavior, and understanding more about why the behavior may be happening. Examples of questions you can ask yourself include; Do the behaviors occur at the same time each day, or with the same person? Does the child have too much downtime? Do the behaviors occur during unstructured opportunities? Do the behaviors occur during transitions? How did I react to the behavior? When and how does a tantrum occur? Is the child attempting to avoid specific situations? It is important to be able to analyze the entire situation surrounding the behavior.

Reacting to the Behavior

Once information is gathered, a plan can be developed. Any plan to deal with challenging behaviors should include prevention, reaction, and teaching. Reaction refers to having a plan in place as to how to react to the behavior when it does occur. Having a plan that is consistent is essential. React to the behavior the same way each time to help the child begin to understand what is expected. When disruptive behaviors do occur, the child should be given as little attention as possible with limited eye contact and limited conversation. Providing the least amount of attention reduces the opportunity to reinforce the disruptive behavior.

Proactive Procedures

The goal of prevention and using proactive procedures is looking at the environment. Creating a new schedule or routine may keep the behavior from occurring or escalating. Organizing materials and looking at the physical arrangement of space may create a less stressful environment. It is important to anticipate behaviors to be able to redirect or prevent situations that might lead to challenging behaviors.

The use of reinforcement is very effective and essential in changing behavior. Reinforcement increases the likelihood the behavior will occur. It can consist of verbal praise, tangible items, or favorite activities. Let your child know when they are behaving appropriately! If they complied with your directions, praise them for it. Tell them exactly what they did right, "I like the way you sat in your seat during dinner". Ask your children to do things that they can do well, so you can reinforce them for being good.

Reinforcement and positive feedback needs to be consistent all day long. A child can "earn" a desired activity by setting the expectation, "first clean your room, then you can use the computer". Just be careful not to bribe! The child should not always be receiving something tangible, especially for

Preemie of the Month Update: Jacob Leaf

Jake was born on May 2, 2003, thirteen weeks early and weighing only one pound, seven ounces. He spent 19 weeks in the NICU and when he was finally released he brought an oxygen tank and monitors home with him. He ended up back in the hospital 19 days later and it was determined that milk/formula was going into his lungs when he ate and when he refluxed. He then had surgery to correct his reflux and a feeding tube placed. That first winter was long, but Jake continued to make strides forward and it is hard to believe that the little boy I see today had such a rough start.

When he was first featured as Preemie of the Month he was delayed in every area of development. He received services from Early Intervention and is now in the Special Education Preschool at our local elementary school. I believe that starting his therapy early has been the key to his success.

Although he did not walk until he was over two years old, he now runs around our playground trying to keep up with his "kindergarten friends," his term for the older kids in our neighborhood. He received speech therapy for a speech delay and now he never stops talking. His is so curious about the world and is constantly asking, "Why?"



Jake and Sarah sporting matching Monkey PJs

The area that has been our biggest struggle is feeding and weight gain. Jake finally got his g-tube removed in April, but still continues to be less than the 5th percentile in weight. We take him to a feeding clinic at Children's Hospital in Washington, DC and have been doing intensive therapy since he was 19 months old. I am still amazed every time he actually asks for something to eat! We have taken the "whatever it takes" approach to his weight gain and every night he gets a bowl of ice cream before bed, even if he didn't finish his dinner.

The thing that makes me most proud is that he is such a wonderful big brother to his little, full term, sister, Sarah. He was just over two when she was born and loved her from the moment he saw her. Watching them together reassures me that despite all the struggles that prematurity brings, he is fully developed in the most important area, knowing how to love and be loved.

Deborah Leaf is a member of the Premies Today board and a Family Nurse Practitioner working with developmentally disabled adults.

Recipe of the Month: Lazy Man's Mashed Potatoes

This is an easy and tasty recipe guaranteed to get some major calories in to you little one. It is also easy to modify to accommodate tolerance for different tastes and textures.

Prep time: 45 minutes

Serves: 10

Serving size: 3/4 cup, 350 calories/serving

Ingredients:

Potatoes:

4 c. prepared instant potatoes

1 1/2 c. shredded cheddar cheese

1/2 c. sour cream

3/4 c. parmesan cheese

9 slices of bacon, fried and crumbled

1/4 c. onion, chopped finely

salt and pepper, to taste

1 clove of garlic

Topping:

1/4 c. butter, melted

1/4 c. grated parmesan cheese

3 slices bacon, crumbled

1 c. dry bread crumbs

Directions:

- 1) Preheat oven to 350 degrees Fahrenheit.
- 2) In a large bowl, mix together mashed potatoes, cheddar cheese, sour cream, parmesan cheese, bacon, onion, salt, pepper, and garlic.
- 3) Place potato mixture in a greased 2-quart casserole dish.
- 4) To make the topping, place the melted butter, parmesan cheese, bacon, and bread crumbs in another bowl and mix well.
- 5) Spread topping mixture over potato mixture.
- 6) Bake for 30 minutes or until topping is golden brown.

continued from cover, Alexander's Story

band and I feel strongly that Alexander would not be here with us today if he had not been born at INOVA Fairfax. We are forever indebted to all the remarkable doctors and nurses who helped save his life.

Our journey after the NICU has been challenging but in a different way. Alexander came home the day before Thanksgiving during RSV and flu season. We voluntarily isolated ourselves from all our friends and only allowed immediate family to come over to visit. Six months later we were finally allowed to take him out in public for the first time. Our isolation at times was very difficult to deal with, especially after the 5 long months we had spent at his bedside in the NICU. But it was worth it, Alexander was never admitted back into the hospital during his first year.

Today we are getting back into the swing of life. I dare now to touch Alexander (sometimes) without first slobbering my hands with anti-bacterial lotion. I have learned not to outwardly cringe every time a stranger grabs his hand. Occasionally I will just run his toys under tap water, instead of disinfecting them, when they fall to the floor. Little by little, preemie step by preemie step, we are getting back to normal. When I hear my son laughing and playing with his toys I think to myself, "Isn't life beautiful?" It is indeed.

**Are you interested in
joining a Preemie
Playgroup?**

**We are currently starting a play-
group in Loudoun County, VA.
Contact Ashley Hall at
ashleyhall@preemiestoday.org
for more information.**

Or

**If you are interested in starting
a playgroup in your area contact
Julie Kipers at
juliekipers@preemiestoday.org
to find out how to get started.**

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everyday expectations. Mix it up by using social praise at times, and when they have gone above and beyond what you expected, let them have that special "item" as a surprise.

Teaching New Skills

Teaching refers to teaching a new skill or replacement behavior. This replacement behavior would be the appropriate way to handle a frustrating situation, ask for a break, or gain an adult's attention. The teaching of a new skill should always occur on its own, not at the time the undesirable behavior is occurring.

Examples of skills that may need to be taught would include learning words to express frustration rather than hitting, or being able to accept the word "no", or making choices. A child may need to learn play skills to play cooperatively, learn how to sit and attend for longer periods at a time, or participate in independent activities without adult support. The new skill being taught should become the replacement for the undesirable behavior. This piece is often left out when dealing with behaviors, but it is essential to give a child the strategies he needs to deal with challenging situations.

Tips for Using Discipline

There are essential tips for using discipline. Discipline has to do with teaching. It is important to catch a child being good! It is too often that we only react to the undesirable behavior. As stated before, let your child know when they are displaying appropriate behavior. Label the positive behavior so they know what is expected. An ineffective strategy would be telling a child what he should not do such as "no hitting". It is more effective to be specific by stating, "You need to keep your hands to yourself".

Focus on being consistent and using proactive and positive strategies as much as possible. Remember, behaviors will not change immediately. They actually may get worse before they get better, but that is a sign that the process is working, stick with it!

Challenging behaviors are frustrating. Taking the opportunity to step back and to begin to analyze the entire picture may provide new insight as to how to approach the situation.

This month's contributor is Mary Beth Hill M.Ed. and specializes in Early Childhood Education.

Local News:

Preemies Today Board: Call for Nominations!

Preemies Today is seeking nominations to join our elected Board for September 2007 through August 2008.

Do you want to help other families affected by prematurity? Do you want to help shape the direction of Preemies Today? Do you just need an excuse to get out of the house? Then run for a position on the Preemies Today Board of Directors. It is a great opportunity to get involved with other families and help the preemie community in the Metro DC region and beyond.

The Board will consist of seven members, but can be up to 12. All Board Members are expected to attend meetings and donate time to the Organization. Each Board Member will be asked to either serve as an Officer (President, Chairman, Secretary, or Treasurer) or as the Chairperson/Co-Chairperson of a Committee. Other duties include: participating in steering the direction of Preemies Today over the next year, seeking new fund-raising opportunities, planning activities for the members and voting on important issues such as the budget. The Board is also a great way to make connections with the members of Preemies Today and help out other families dealing with issues related to prematurity.

If you are interested in becoming a Board Member, or nominating someone to the Board, please contact elainenoto@premiestoday.org by **August 15th**. You may nominate up to seven people to the Board. Further, we welcome those Members from out-of-State who are interested in joining our Board; our Membership now spans over 25 States so your input is extremely helpful! Out-of-State Members of the Board will be able to join our Board Meetings via telephone conference.

Preemies Today Annual Meeting of Members

Join Preemies Today for our Annual Meeting of Members and let your kids explore "Under the Sea."

Don't let your summer end as we bring back the beach with a marine biologist and his creatures from the ocean. Special guests will include a giant sea snail, hermit crab, sea star, sea urchin, toad fish, blue damsel, clam, mussel, spider crab, and puffer fish! Our Annual meeting will follow this 30 minute presentation.

Date: September 8, 2007

Time: 2pm

Where: Tysons Pimmit Library
7584 Leesburg Pike
Falls Church, VA 22043-2099

Tysons Pimmit Library is less than a mile from exit 47B of the Capital Beltway (495) and is also close to 66 and 123.

A Note From Our Chairman:

Your participation is crucial to creating a sustainable organization dedicated to supporting families with premature infants and children. If you would like to discuss any of the above, or would simply like more information about our Organization before you decide, please contact me at elainenoto@premiestoday.org. Both Mary Beth Hazelgrove, our President, and I are happy to share with you the current Boards' Vision, 2007 Goals and Objectives and future plans.

Thank you,
Elaine Noto
Chairman of the Board

Preemies Today Support Programs:

"A Friend to Talk to"

Our "Friend to Talk to" support line is up and running. Please feel free to give us a call and one of our preemie parent volunteers can offer you some much needed support. The support line telephone number is 703-552-0163, or toll free number at 1-888-712-3208.

NICU Support Group

INOVA Healthsource is continuing to offer a NICU Support group for NICU families at INOVA Fairfax. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN and is a great opportunity to talk about your experience in the NICU. For more information contact INOVA Healthsource at 703-204-3366.

Take a Break

Preemies Today offers meal preparation assistance and additional support for preemie families in crisis. If you are in need of assistance or would like to volunteer to help others,

please contact Susan at susan.boucher@starpower.net.

Preemies Today Online Chat

Join us for our monthly online chats. This is a great outlet for new parents who still can't get out for our support groups. For more information contact Julie at jkipers@lmi.org

Local Support Groups

Local support groups are going strong! On every 2nd Wednesday at 7:30 pm we hold our local support group meetings. For more information email Mary Beth at marybethhazelgrove@premiestoday.org

Yahoogroup!

Come and join our yahoogroup and meet some of our wonderful parents where you can exchange information on preemie parenting. You can subscribe at <http://groups.yahoo.com/group/PreemiesToday/>

Helpful Resources:

National Resources

Social Security Administration:

1-800-772-1213

www.ssa.org

Many premature infants qualify for Social Security Disability, regardless of parents income. Ask your NICU social worker or contact the SSA to see if your child qualifies.

The State Children's Health Insurance Program (SCHIP)

<http://www.insurekidsnow.gov/>

All states have a health insurance plan for uninsured children under the age of nineteen whose families meet the income cap. Go to the above website to find your state's program.

March of Dimes

1-800-326-BABY

www.marchofdimes.com

The March of Dimes has a wealth of information about preterm labor and premature birth. It is also a great place to start in looking for support in your area.

Sidelines National Support

1-888-447-4754

www.sidelines.org

Sidelines provides support for pregnant women on bed rest and those dealing with the after effects of bed rest.

SIDS Mid-Atlantic

(703) 933-9100

www.sidsma.org

Look here for information on how to prevent Sudden Infant Death Syndrome.

Metro Washington, DC Resources

Social Services- Virginia

Alexandria- (703) 838-0700

Arlington County - (703) 228-1550

Fairfax County- (703) 324-7500

Fauquier County- (540) 347-2316

Loudoun County- (703) 777-0353

Manassas City- (703) 361-8277

Manassas Park - (703) 335-8898

Prince William County- (703) 792-7500

Social Services, Maryland

Montgomery County- (240) 777-1245

Prince George's County- (301) 909-7025

Social Services, Washington, DC

Department of Human Services- (202) 671-4200

Early Intervention/ Infant Toddler Connection

This is a federally mandated program available in every state to screen and treat children under the age of 3 for developmental disabilities and delays. If you have any concerns about your preemie's development, contact your local office to have your child tested. Services are covered by most insurances and are billed on a sliding scale.

Virginia

Alexandria- (703) 838-5060

Arlington County- (703) 228-1630

Fairfax County/Falls Church City- (703) 246-7121

Loudoun County- (703)-777-0561

Prince William- (703) 792-7879

Washington, DC- (202)727-8300

Maryland

Montgomery County- (240) 777-3997

Prince George's County-(301) 265-8415

WIC

Provides food, nutrition counseling, and access to health services to low-income women, infants, and children under the Special Supplemental Nutrition Program for Women, Infants, and Children, popularly known as WIC.

Virginia

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

Washington, DC- (202) 645-5662

Maryland

Montgomery County- (301) 762-9426

Prince George's County- (301)856-9600

**For a more complete listing of resources please go to:
www.PremiesToday.org**

Membership/Subscription Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie playgroups, and "A Friend to Talk To," our call-in line for parents and families of preemies. Membership in our organization is free.

For a free subscription to our newsletter and to join Premies Today please email us at info@premiesto-day.org or you may go to our website at www.PremiesToday.org and click on "Join us."

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**PREEMIES
TODAY**

*P.O. Box 523525
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Do you need to talk to someone who understands the preemie experience? If so, call the "Friend to Talk to" line at **1-888-712-3208**