

# PREEMIES TODAY

*National Premie Families Support Network*

## A Sixteen Year Old Shares His Personal Premie Story

By Brandon Tang



*Sixteen year old Brandon Tang pictured in a recent photo in 2010.*

The day I was born was the most memorable day of my life for all the wrong reasons. Unlike most people, who view their birthday as a day to celebrate their happy entry into the world, my birthday was significant to me because I arrived at the wrong time--10 weeks before my expected due date. Had I been born three weeks earlier, when my mother's water started to leak, my story might be very different.

I was born ten weeks early, at twenty-nine-and-a-half weeks weighing a whopping two pounds, two ounces. I was not just a premie, but a "micro-premie." My head was the length of a thumb and my entire body could probably fit in the palm of a hand. I was anemic, jaundiced, and prone to infections. I had trouble with routine physical functions such as feeding, crawling, and walking--actions which came naturally to most full-term babies. When I entered school, I was under the 5th percentile of all American kids in size and weight, meaning that I was always the smallest and shortest kid in my class. I had difficulty performing simple tasks that require coordination such as manipulating scissors, kicking a soccer ball, and running without tripping over myself. Yet gradually, as I grew older, I became more aware of my condition. I began making small choices as simple as drinking an extra glass of milk in the hopes of one day growing up to not be the shortest in

my class. With persistence and determination, I can proudly say that my hard work has paid off--I am now five feet 11 inches tall, above average in my class.

The problems I faced early in life because of my premature birth taught me to be flexible and accepting when facing challenges. While I no longer struggle to walk without stumbling, I still deal with some lasting physical conditions. As a member of the boys' cross-country team during my high school freshman year, I suffered a nagging ankle injury late in the season that forced me to stop running. The physical therapist determined that my injury was chronic because of my underdeveloped ankle. Even though I will not be able to run with the cross country team for now, I remain grateful for the chance to participate in a sport I once thought was beyond my physical ability. My experience as a premie has taught me that I can overcome most setbacks with hard work and determination. Instead of giving up on high school sports, I have joined the badminton team while continuing to strengthen my ankle to tackle cross country.

A better understanding of the correlation between my neurodevelopmental milestones and my real age, not my birth age, has taught me to remain positive during challenging times. Instead of battling feelings of frustration and defeat, I have learned to refocus my energy towards forming strategies to understand concepts. While I cannot attribute all my struggles to my real age, it helps me un- **Continued on page 3**

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**Founded:**  
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**website:**  
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**Preemies Today** is a 501(c)3 non-profit organization whose mission is to provide outreach and support programs to families of infants born prematurely beginning at birth and throughout childhood.

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In-Kind--8 hours  
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Purchase *No Bigger Than My Teddy Bear* by Valerie Pankow for \$6.95. Proceeds will benefit Preemies Today. Contact info@preemiestoday.org  
For tax-deductible donations visit www.preemiestoday.org. Please consider honoring your preemie by making a donation in their name.

*"For it is in giving that we receive." St. Francis of Assisi*



## Happy Mother's Day from Preemies Today!

*Making the decision to have a child  
is momentous. It is to decide forever  
to have your heart go walking around  
outside your body.*

Elizabeth Stone

Preemies Today is proud to send 400 Mother's Day cards this year to mothers of newborn infants in 18 NICUs. Thank you to our Stone Middle School student volunteers for helping to prepare the cards.

derstand why the classmates in my calculus class can grasp the advanced mathematical concepts much faster. By developing strategies to facilitate my understanding of these concepts and keeping up my efforts, I feel that I am improving and closing the gap of understanding.



**Brandon's first photograph, taken by a NICU nurse, in 1994 at three weeks of age.**

While these setbacks might seem devastating in the short-term, I have determined that there are worse things in life than a bad grade or a missed sports season. Instead of being discouraged that I cannot continue with cross country, I am thankful for the opportunity to participate in a sport I never dreamed of playing when I was younger and smaller. Instead of losing hope because of a bad grade, I am grateful that I am learning how to take the derivative of time when I once had trouble with the basic concept of time. As Albert Einstein, a famous preemie put it, "There are two ways to live your life. One is as though nothing is a miracle. The other is as if everything is."

More than a half million babies in the United States, one in every eight, are born prematurely each year. Those who sur-



**Brandon pictured here at sixteen months old in 1995. You can see a small bald spot on the left side of the photo where his head was shaved during his NICU days.**

vive may face lifelong health problems such as mental retardation, cerebral palsy, breathing and respiratory problems, vision and hearing loss, and feeding and digestive problems. With advances in medicine targeted towards improving prenatal and neonatal care, these premature babies now have a much better quality of life and survival rate. I am one example of the many thriving premature babies who have benefited from the work and commitment of so many. I want to share my story because the community needs to know that the investments made to advance the knowledge and practice of prenatal and neonatal care do make a huge difference in a preemie's life and I thank you every day.

## **Transitioning Out of Early Intervention**

**By Yokaira Landron, Preemie Mom and Parent Advocate**

**Early Intervention (EI) services will end when your child turns 3-years old or before if they are no longer eligible.**

When EI ends some children are eligible for Special Education services and go to school. Others attend Head Start, pre-school, daycare, or stay home. It is important to prepare yourself for the end of EI and make plans for your child.

You are going to hear the word "transition" quite often. Transition refers to the period of time before, during, and just after EI ends.

We recommend that you start this process when your child is between 2 years and 2.5 years.

**Good Luck during the Transition and we really hope these tips can help you.**

1. Referral is made by EI to the School District in your area, only if you already agree with it.
2. Within five calendar days of the receipt of the referral, the school notifies the parents and requests consent for an evaluation.

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# 10 Life Lessons from the NICU



JBRyson/istockphoto.com

*This article was written by Sue Ludwig. Sue is the President and Founder of the National Association of Neonatal Therapists. She is a consultant to neonatal intensive care units around the country, a national speaker, and a published poet. She lives in Ohio with her husband and two children.*

Parents: This article was written for the National Association of Neonatal Therapists and then broadened to help the world understand a little of what we experience everyday in the NICU. Parents of preemies have taught me so much of what I know about the importance of connection in the NICU. You are brave, resilient and dedicated. Your babies changed my life.

If you've never stepped foot in a neonatal intensive care unit (NICU), you might be tempted to think it's a bustling place filled with baby noises like fussing, crying, and cooing. You'd be wrong. Mostly the babies are quiet. There are monitors, pagers, and ventilators beeping, phones ringing, staff and parents talking, but oddly a noticeable lack of fussing coming from the babies. It's hard to cry loud with small lungs.

How is it that these fragile, nonverbal babies have so much to teach me? Like any of us, I learn in direct proportion to how much I pay attention and by how much I intentionally engage in my work versus just going through the motions. When you pay attention, these babies speak volumes.

**Here are 10 lessons I've learned from the babies in the NICU:**

**1. Being born early does not mean preemies are less human, less valuable, or less worthy. Preemies are simply less prepared.**

Pregnancies are considered full term by 37 – 40 weeks. When a mother has her baby at 25 weeks gestation, no matter what I tell her, she often feels shame that her baby is still in the process of developing. Well, who isn't? A few years ago I was writing up research for publication. I thought I was a decent writer. After spending countless hours writing this paper, my mentor came back and basically told me to start over. I sobbed on the spot from exhaustion and the shame of feeling inadequate for this work despite my efforts. I was ashamed to still be developing as a writer.

Here's the thing. We're always in process! We are each starting over and over again in an endless cycle of learning and development. Parents of preemies should have no guilt, no blame, and no shame. They had no control over their preterm birth.

## **2. We each communicate differently.**

It's easy to judge another person when she communicates differently, slower, or in a different dialect than you.

Preemies have taught me to listen first, assume nothing, and leave judging for the Olympics. More importantly, I learned that I am responsible for half of every interaction with someone. If I am busy thinking about what the other person should be doing or saying, I am likely not present for my end of the communication.

## **3. Small and feisty goes a long way!**

Visit a NICU sometime to watch this one in action!

## **4. Environment Matters.**

Loud noises are stressful. NICU babies respond to this stress by being startled frequently, spending less time in a deep sleep, and having changes in their heart rate and other vital signs.

What about your environment? When you walk into the door to your home, do your surroundings add to your stress or decrease it? Is it cluttered, do you have space, do you have freedom to move? Are the sounds pleasant or are they just noise? The environments we create for ourselves directly affect our mood, our productivity, and our well-being. The babies have taught me that we thrive in an environment that serves us.

## **5. Connection heals.**

There's nothing better for a baby than loving connection with her mother and family.

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Recently a mother in our NICU held her tiny baby on her chest. The baby was still on a ventilator. This is known as “Kangaroo Care” or “skin to skin” holding. This mother, like so many before her, said that this was the only activity that truly allowed her to feel like a mother since her baby was usually in an incubator. Babies breathe and sleep on their mothers amazingly well even in this fragile state.

We are meant to be in connection with others. Separation from that connection leaves us more vulnerable and less likely to maintain health. When our connections are loving and consistent, we thrive. Often when we feel vulnerable, angry or sick it's because we've stepped away from the connections that heal us.

## 6. Eating Should Be Enjoyable!

In the NICU we're obviously concerned with how much weight babies are gaining. In our quest for improving weight gain, we often overlook the significance of the actual experience the baby has while eating. We pay too little attention to the fact that feeding is a bonding experience, social and nurturing. But we know that many premature babies nationwide have issues with feeding long after they've left the NICU. I believe that part of the problem is that hospitals often view feeding more like a medical intervention than a nurturing experience.

We should enjoy eating! But we often forget it's a nurturing experience for our bodies and feed only our emotions or are completely distracted while we eat, giving no attention to the experience or the food. Babies have taught me that eating should not be automatic. It should be intentional and engaging.

## 7. Tenacity is an inside job.

About a decade ago a boy in our unit was born weighing just about a pound. He had significant lung disease months later when he was discharged home. Now, at age 9, he is the fastest boy on his soccer team. Who'd have thunk? That young boy taught me that tenacity isn't definable at the surface. It's something deeper, more elusive than brawn and background. It comes from inside. You know you are stronger than anyone would guess, even when you weigh just a single pound! When I reflect on that boy's strength I think, “Who am I to think I can't achieve something?”

## 8. Comfort and sleep are crucial to healing.

This is true for both mothers and babies. Mothers of babies in the NICU are often torn between taking care to recover themselves and being in the NICU with their baby. Moms need to sleep, rest, and take some breaks from being in the NICU in order to take care of themselves and their babies.

Babies in the NICU are doing very important work when

they are asleep. Factors influencing growth and crucial brain development happen when they are sleeping. It's important to protect this sleep.

## 9. There are times for fighting and times for letting go.

For a premature or sick baby, most days are about fighting and growing. They are about overcoming one more hurdle, using one less tube, and making one more step toward going home. Most babies win that fight. At other times, when all that medicine and love have to offer is not changing the tide, the nurses and doctors do the impossible job of helping a family lovingly let go.

On the letting go days, I know only to go home and hug my own children in humble gratitude. Loss is a powerful instructor. Life is precious, yes. These babies teach me that it is hard to comprehend the gravity of that truth until we are asked to let it slip away.

## 10. Fragility and strength are not necessarily opposites.

If you look around the NICU and witness these tiny babies defying what seems reasonable for such a small person, you observe that fragility is often just strength's first teacher.

I have rarely witnessed a population of patients that inspire such loyalty in their caregivers. Across the country I've noted that the NICU team appears, in my experience, to love this work and maybe because we have the best teachers.

To learn more about the National Association of Neonatal Therapists please visit us at: [www.neonataltherapists.com](http://www.neonataltherapists.com)

To contact Sue Ludwig: [info@neonataltherapists.com](mailto:info@neonataltherapists.com)



*Sue Ludwig is the President and Founder of the National Association of Neonatal Therapists. Ms. Ludwig is a practicing neonatal occupational therapist at University Hospital in Cincinnati. She is a sought after national speaker, consultant, writer and educator. Sue has published articles related to infant-driven feeding and developmental care in the NICU. She is also a published poet.*

*Sue is a member of the American Occupational Therapy Association and an ex-officio member of the Education Provider Committee for the National Association of Neonatal Nurses.*

*Sue lives in Ohio with her husband and two children.*

# The Vestibular System--Part 2

by Richard Feingold, Co-founder of Creative Health Solutions ([www.creativehealthllc.com](http://www.creativehealthllc.com))

***Vestibular: the sense of movement; input from the inner ear about equilibrium, gravitational changes, movement experiences and position in space.***

***Sensory-Processing-Disorder.com***

Vestibular challenges have genetic and environmental origins. Genetically, the neural pathways responsible for processing vestibular sensations may be compromised; the cilia receptors in the canals may not be appropriately developed, etc. Environmentally, the vestibular system requires stimulation in utero before birth. The mother may have required bed rest for the third trimester. After birth, related or unrelated medical conditions may have limited motion. Likewise we can imagine causes for over stimulation in frequency, intensity, or both.

There are obvious and not so obvious symptoms. While it's important to be observant, it is essential to obtain a professional assessment and confirmation from a physician or occupational therapist. Since this article is not intended for diagnosis, I'm limiting the examples to a few representative ones: apparent lack of balance, proprioceptive difficulties (understanding the relative position of your body parts), craving for vestibular stimulation (swinging, spinning, rocking), avoidance of the same, apparent hearing problems, and difficulty in age appropriate movements requiring balance.

Try to imagine a world where everything is unsteady, out of balance. A world in which you are uncertain of what is up and down can be very confusing. A world you can't tell if you're being accelerated or even moving if you close your eyes can be very scary. Now, try skating on ice. If that's not hard enough, consider that children with these challenges don't even have the experience of accurate proprioception. By contrast, Helen Keller and many others have successfully modeled, navigated, and understood the world through proprioception and touch alone.

Let's take one more view from the other side: over-stimulation. Imagine yourself at a party with loud music and louder talking; trying to hear what someone is asking from the other side of the room can be very difficult. Now try to learn a new language in that environment.

One final thought about this. An over-stimulated vestibular system may seem problematic, but perhaps not so bad. That is until you recognize the common characterization of over-stimulated nerve endings is pain. Imagine constant pain coming from your most basic sense. This pain cannot

even be expressed because a child cannot speak, has no words, no basis, or no reference point from which to speak. That is why we must listen with our eyes, our hands, and our hearts.

Clearly understanding the situation is critical. In our therapy, within the bounds of safety and prudence, we let the child indicate their treatment. That is, we listen with our ears, eyes, hearts, and hands. If a child is drawn to something, there is a reason; if a child is repulsed by something, there is also a reason. When a child runs into the Sensory Gym and asks to spin or hang from the zip line or jump on the pogo stick, we need to learn and understand and build on that. And when a child pushes away from these devices, there is just as important a message and we must learn from it.



Please consult with your health care provider for applicability to your child or yourself.

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## Characteristics of Vestibular Dysfunction

**These checklists will help you gauge whether your child has vestibular dysfunction. As you check for recognizable characteristics, you will see emerging patterns that help explain your child's out-of-sync behavior:**

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**1. Hypersensitivity To Movement (Over-Responsive):**

- Avoids/dislikes playground equipment; i.e., swings, ladders, slides, or merry-go-rounds.
- Prefers sedentary tasks, moves slowly and cautiously, avoids taking risks, and may appear "wimpy".
- Avoids/dislikes elevators and escalators; may prefer sitting while they are on them or, actually get motion sickness from them.
- May physically cling to an adult they trust.
- May appear terrified of falling even when there is no real risk of it.
- Afraid of heights, even the height of a curb or step.
- Fearful of feet leaving the ground.
- Fearful of going up or down stairs or walking on uneven surfaces.
- Afraid of being tipped upside down, sideways or backwards; will strongly resist getting hair washed over the sink.
- Startles if someone else moves them; i.e., pushing his/her chair closer to the table.
- As an infant, may never have liked baby swings or jumpers.
- May be fearful of, and have difficulty riding a bike, jumping, hopping, or balancing on one foot (especially if eyes are closed).
- May have disliked being placed on stomach as an infant.
- Loses balance easily and may appear clumsy.
- Fearful of activities which require good balance.
- Avoids rapid or rotating movements.

**2. Hyposensitivity To Movement (Under-Responsive):**

- In constant motion, can't seem to sit still.
- Craves fast, spinning, and/or intense movement experiences.
- Loves being tossed in the air.
- Could spin for hours and never appear to be dizzy.
- Loves the fast, intense, and/or scary rides at amusement parks.
- Always jumping on furniture, trampolines, spinning in a swivel chair, or getting into upside down positions.
- Loves to swing as high as possible and for long periods of time.
- Is a "thrill-seeker"; dangerous at times.
- Always running, jumping, hopping etc. instead of walking.
- Rocks body, shakes leg, or head while sitting .
- Likes sudden or quick movements, such as, going over a big bump in the car or on a bike.

Used with permission. *The Out-of-Sync Child: Recognizing and Coping with Sensory Processing Disorder*, 2nd edition (Perigee, 2005), by Carol Kranowitz, M.A.

***Transition, Continued from page 3***

3. The School receives the consent for evaluation from the parents.

4. The next phase of transition will be completed within 45 school working days. An assessment is first completed within the first 30 school working days. If requested, written summaries are provided to the parents two days before the Team Meeting. The Team is the group of people that are going to be part of your child success which will include the parent(s) or guardians.

If a child qualifies for services, then an Individual Education Plan (IEP) is written and placement options are discussed. Children can receive home-based services or school-based services as determined by the Team.

5. Within 30 calendar days the parents review the IEP, choose options, sign, and return the IEP to the school.

6. The school implements the program with parental approval.

**March of Dimes**.....[www.marchofdimes.com](http://www.marchofdimes.com)  
The March of Dimes offers a wealth of information about preterm labor and premature birth.

## **Social Security**

**Administration**.....[www.ssa.gov](http://www.ssa.gov)  
Many premature infants qualify for Social Security Disability regardless of income. Go to the above website to find your state's program.

## **State Children Health Insurance Program (SCHIP)**.....[www.insurekidsnow.gov](http://www.insurekidsnow.gov)

All states have a health insurance program for uninsured families that meet the income gap. Go to your state's program.

## **Developmental Delay**

**Resources**.....[www.devdelay.org](http://www.devdelay.org)  
Resources, articles, and information for children experiencing developmental delays.

## **Child Find**

Preschool Child Find serves as a resource for preschool children and their families by providing therapy or educational services in the home or in various local elementary schools for children that qualify starting at age two through age five. This program is provided at no cost. If you suspect your child has a developmental delay, call now. It may take up to four months or longer to begin services.

## **Virginia**

Alexandria (703) 824-6708

Arlington (703) 228-6042

Fairfax County

(703) 876-5244 Devonshire office,

(703) 317-1400 Virginia Hills office

Falls Church City (703) 248-5655

Prince William County (703) 791-8857

## **Maryland**

Montgomery County (301) 929-2222

Prince George's County (301) 808-2719

## **Washington DC**

(202) 727-8300

## **Social Services**

### **Virginia**

Alexandria (703) 838-0700

Arlington (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

### **Washington DC**

Department of Human Services

(202) 671-4200

### **Maryland**

Montgomery County (240) 777-1245

Prince George's County (301)909-7025

## **Early Intervention**

This is a federally mandated program available in every state to screen and treat children under the age of three 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. Waiting lists may exist. Call as soon as possible.

### **Virginia**

#### **Infant and Toddler Connection**

Alexandria (703) 838-5060

Arlington County (703) 228-1630

Fairfax County/Falls Church (703) 246-7121

Loudoun County (703) 777-0561

Prince William (703) 792-7879

### **Washington, DC**

#### **Office of Infants and Toddlers With Disabilities**

(202) 727-8300

### **Maryland**

#### **Infant and Toddlers**

Montgomery County (240) 777-3997

Prince George's County (301) 265-8415



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