

Caring for a premature child, part 5: Profile of a growing preemie

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This article is part 5 of a several part series (see [part 1](#), [part 2](#), [part 3](#) and [part 4](#)) detailing the intricacies of parenting premature children.

This installment focuses on Madison, a preemie born at just 26 weeks gestation and weighing a scant 1 pound and 14 ounces. Madison's mom, Mary Beth Hazelgrove, is the Executive Director of [Premies Today](#). She has provided us with an intimate glimpse of a typical day for Madison, who is now in grade school, and gracefully coping with the effects of prematurity.

Valerie: Please share Madison's background with us:

Mary Beth: Madison was born at 26 weeks gestation, with a [grade 2/3 IVH](#) (Intraventricular Hemorrhage), which led to hydrocephalus and a [VP shunt](#). Her shunt was completely replaced at age 5. Madison came home from the [NICU](#) on oxygen and monitors. She has had delays since birth and we have received [occupational](#) and [physical therapy](#) (or both) since then. We were told in the hospital she was high risk for severe disabilities but she has no severe disabilities. She is labeled in school as learning disabled. Although, I hate labels!



Valerie: Please outline a typical day for your daughter, Madison.

Mary Beth: We have a pretty busy schedule. Madison is currently participating in a summer school program and she receives instruction in Math, Reading, and Writing three hours a day for 4 weeks. Madison wakes up each day on her own at 6:30 am. She eats a small breakfast—usually toast or some frozen pancakes.

After breakfast she listens to a specialized Music CD which is part of her therapeutic listening program given to her by her occupational therapist. While listening to the CD she draws pictures or sometimes we work on her CCD lessons.

She then quickly brushes her hair, teeth, and helps pick out a snack for the day and is out the door. She is picked up by a school bus near our home at 7:30 am. Madison may feel anxious and worries about missing the bus in the morning even though we are never late.

Valerie: What does Madison do for the rest of the day, after such a full day of schooling?

Mary Beth: Madison comes home at 11:30 AM, again on the bus; and she is dropped off very close to our home. We will eat lunch and relax, play, or watch some TV with her 4-year old sister.

She may also play with our next door neighbor, ride her scooter, or bounce her basketball with her sister. She is looking forward to learning to ride a bike. She also loves to go to the pool in the afternoon or early evening. We usually go on days that she does not have Occupational Therapy. She has made great progress in the pool since last summer. She is quickly learning to navigate all depths of our pool from 3-5 feet. She is also beginning to learn elementary aquatic strokes. She loves the pool!



Each evening after dinner we try to go up to the third floor of our town home where the girls' rooms are located. We read books, the girls take baths, and we also try to fit in a few of Madison's Vision exercises. Some examples of these activities include making snow angels on the carpet and isolating different parts of her body, working with play dough and isolating different parts of her hands to increase body awareness, and doing Duck and Pigeon Walk which works on integrating the Moro reflex which normally integrates during infancy.

After Vision on Saturdays we usually go to the pool and relax. Sometimes we bring a picnic lunch. Sundays are similar with the exception of going to Church in the morning.

As an aside: I am home schooling her Catholic education for 1st grade. I felt it was too much to do during the school year and feared it might frustrate her being in a classroom without support. We have to complete the curriculum and she must take a test in August to advance to second grade where she will have her 1st Communion. She is doing a great job and has already learned all her prayers.

Valerie: What is the overall picture of Madison's therapies; how often does she see therapists and at what expense?

Mary Beth: On Mondays she goes to Occupational Therapy for an hour to work on bilateral coordination, fine motor skills, and sensory integration. She may swing on big swings in different directions to help with her sense of movement, work on rhythm, or work on fine motor activities. She has been going to this therapist for about a year now and she is making great progress. She previously ran with an uncoordinated gait and her running is beginning to look a lot smoother.

She has been seeing a [Developmental Optometrist](#) on Saturday mornings since February. We were very fortunate to receive United Health Care Family Grant to help cover expenses for this therapy which costs will amount to around \$5,000. This particular therapy helps with school-related vision problems such as copying from the board and reading. Madison wears glasses although her acuity continues to be within a normal range. Her glasses help her eyes not have to work so hard to focus. Vision Therapy helps with her visual tracking and improves her ability to use her eyes better together.

Valerie: It is my understanding, as a fellow "preemie parent," that emotional problems are completely typical among developing preemies, and can manifest themselves at any point in development.

Mary Beth: Every other Thursday we go to see a clinical social worker and participate in psychotherapy for one hour. Madison started having some classic separation anxiety issues whenever I would leave the room or take our new puppy outside. Her therapist is quickly helping us resolve this issue and continues to help with issues surrounding anxiety which is not uncommon in some older preemies. She also helps with some other impulsive behaviors.

Valerie: Madison really is an exceptional and bright girl; and she certainly has achieved so much, despite the encumbrances of prematurity!

Mary Beth: I am always impressed by how hard she works and her motivation to succeed. I know with support there are no



limits to her potential. She is really a great kid. She has some trouble navigating the social world of school but she loves to engage adults in conversation and has an amazing sense of wit. During the school year she has been participating in the Northern Virginia Therapeutic Riding Program. She loves riding horses. It is great to see her enjoy an extra-curricular activity which is so physically and mentally challenging. I know her schedule is very busy and we try to balance what she wants and what we feel she needs to make her life a little easier at home and school.

Stay tuned for part 6 of this series, which will profile Mary Beth Hazelgrove's advocacy and outreach work with Preemies Today, a non-profit group, which is wholly devoted to supporting parents of preemies.

Resources for therapeutic programs:

[Vital Links, Therapeutic Listening](#)
[Freedom Ride \(Orlando\), Therapeutic Riding](#)

Also see: [Caring for a premature child, part 1](#) , [Caring for a premature child, part 2](#) , [Caring for a premature child, part 3](#) and [Caring for a premature child, part 4](#) for additional resources.

Have feedback, tips or questions? Connect with Valerie (fellow proud mama of a preemie) at valerieapowers@gmail.com, or on [Facebook](#).

Photo credits: Madison smiling, in the NICU, current snapshot and riding/Mary Beth Hazelgrove

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