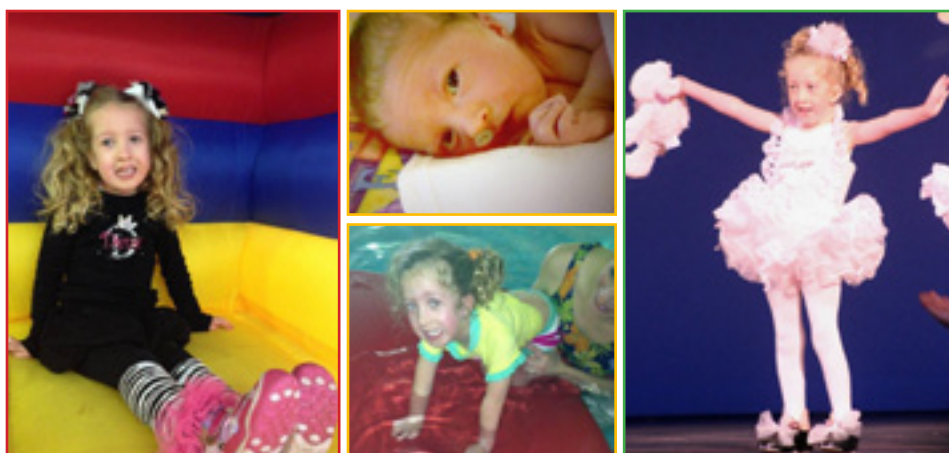


# KIDS UPDATE

SUMMER  
2013

## Miracle Baby Makes Big Strides Orthotic Expertise, Intensive Therapy, and a Determined Mom and Dad Facilitate Mobility



Melissa S. calls her "my miracle baby." With good reason.

To watch her walk, run, play, and dance, you wouldn't think little Demi S. was any different from any other three year old. But she has come a long way since her mom and dad, Melissa and Derek, were told by doctors that Demi may have lifelong physical disabilities and mental challenges.

But the doctors didn't know the determination of the family, who gave Demi every possible chance to succeed. And there is Demi herself, who showed not only resiliency, but also compliancy in wearing her various braces, engaging in physical therapy, and undergoing countless doctors' appointments and medical procedures.

The story begins when, after a normal pregnancy, Demi was born extremely weak and unable to nurse. Demi remained in the NICU for seven days before she was allowed to go home.

"She could not move anything," Melissa explained. "She had no muscle strength, but her heart was strong. She was seen by a neurologist when she was five days old, but nobody was sure what was going on with her."

On day 11, Demi stopped breathing. "The things you find out about yourself when

you are a mom," Melissa said. "I didn't think I knew CPR, but I must have known something because I kept her breathing until the ambulance arrived."

Demi was medevaced to Albany Medical Center where she stayed another 11 days, enduring rounds of tests including a spinal tap. Still, no definite diagnosis was made. The family then had follow-up appointments with physicians specializing in developmental medicine, who cautioned that Demi could be mentally disabled. "That was a lot to swallow," Melissa said. "We weren't sure whether she would ever walk or talk or have a normal life."

The Family began with early intervention therapy. "Every day she started to get a little stronger, but when she was six months old, the doctors started talking about muscle diseases. They suspected that she has a congenital myopathy," Melissa said.

Congenital myopathy is a disorder of the muscles that results in weakness. Milestones such as holding the head up, sitting up, and walking are delayed. Some babies born with the condition have difficulty breathing and feeding. Later some skeletal problems surface, such as scoliosis.

"I looked into all avenues of therapy for her," said Melissa. "We had therapists work with her at our house and we could see with

their expertise she was getting stronger and stronger. We saw the developmental specialist every few months and we eventually learned that she was cognitively fine."

To help strengthen her muscles, Demi's therapy included swimming sessions with Kids Care Pediatric Rehab Services. It was there, when Demi had just turned one, that Melissa met Sampson's certified orthotist Jill Kunz, who was participating in a Kids Care clinic.

"When I met Demi, she was not able to hold her head up or sit unsupported," Jill recalled. "The physical therapist was working with her to strengthen her muscles to develop these skills. The occupational therapist also was working on upper extremity function.

### A PROGRESSION OF ORTHOSES

Soon after that first meeting, Jill became Demi's orthotist and recommended a neoprene TLSO (Thoraco-Lumbo-Sacral Orthosis) to help stabilize and support her trunk and upper extremities. "She had poor use of her hands as well, so we also made tiny neoprene hand supports. She was not your typical sized one year old. She was very petite," Jill said.

The TLSO, combined with intensive physical therapy, helped Demi with her strength and balance and seven months later, she was able to sit unsupported. A milestone reached, but many more to go.

"Therapists were then concerned with the positioning of her lower extremities. She collapsed into pronation, dorsiflexion, and knee flexion so it was hard for her to maintain an upright position due to the muscle weakness," Jill explained.

Rather than a standard AFO (ankle foot orthosis), Jill put Demi in a Cascade DAFO (Dynamic Ankle Foot Orthosis), a thin, lightweight plastic that wraps very closely

continued on next page

continued from previous page

around the foot and ankle. The intimate fit of the shell allows for use of a thinner plastic to precisely correct and control foot position to a degree not possible in a standard AFO. Also, the thinner plastic allows the shell to flex, making the brace more comfortable for Demi.

"The DAFO provided good support and alignment. After about six months, Demi was able to stand independently and was cruising around furniture. Now we had to do something different because she needed something stronger," Jill said.

Demi was fitted with articulating custom AFOs, but she was still having problems with weakness and maintaining knee extension. "We adjusted the AFOs to give her limited motion to be able to maintain an upright position," Jill said.

Demi adjusted to the AFOs and practiced her walking using a posterior walker. Within six weeks, she was able to take her first independent steps – another milestone reached. She was 25 months old.

Demi kept progressing. Although her knee extension was improving, her feet and ankles were still weak, so lower profile SMOs (supra-malleolar orthoses) was fitted. Again, the use of lightweight, thin, and flexible plastic allowed for more natural movement of the feet and ankles while still maintaining proper alignment.

But as mobility increased, other physical problems surfaced including shoulder

subluxation and patella laxity. With congenital myopathy, one of the issues is early onset of scoliosis, and Demi's doctors were monitoring her spine development. Her measurements in the fall of 2012 were 33 degrees at T5 and 27 degrees at T11. It was time for the

scoliosis to be addressed.

The family was relying on Jill to help them make a decision on bracing and requested that she accompany them to the doctor. At first the doctor recommended casting, a traditional method for treating infantile scoliosis, but the family was hesitant to put Demi in that position. They sought a second opinion in Springfield, Mass., and agreed to first try a more moderate approach of using a bivalve scoliosis jacket they received there. Initially, there were some issues with skin irritation and the jacket not holding its position. Jill's solution was to try a low profile scoliosis TLSO. Demi is now comfortable enough wearing the jacket to achieve compliance of 23 hours a day, 7 days a week.

"So far we are doing great with the TLSO," said Jill. "She jumps, she runs, she rolls, she does everything a three-year-old does. It doesn't stop her in the least bit."

The success in wearing a scoliosis brace is dependent on strict compliance to the wearing times and both parents and child are committed to it. Melissa said that Demi is aware of what she needs to do. "For the first week, she would say, 'I know we have to wear the brace,' and then ask, 'is my back better yet?' She is very compliant."

"Having a compliant and supportive family is important," said Jill. "Demi's family is behind her 100 percent. They have given her every opportunity to progress."

Because of Demi's low tone, she may be wearing the TLSO for a longer term than a typical adolescent patient. "As she gets older and gains more muscle strength and skeletal maturity, we may be able to wean her out of it. I'm not sure of the time frame yet. That will be up to the doctors," Jill said.

### A SMART LITTLE COOKIE

Demi is growing normally, and her verbal skills clearly present themselves when she refers to her SMOs as her "orthotics."

"She is just way beyond her years," Jill said. "She is a smart little cookie. She is



always with smiles and giggles. I don't know any other three-year-old that would handle as much as she has been through with that kind of attitude."

Demi still has weekly sessions in speech therapy, occupational therapy, and physical therapy. She also was recently fitted with hearing aids in pink – her favorite color. "She could always talk, but she was missing whispers and consonant sounds. Since she has the hearing aids, her speech is amazing," said Melissa.

She is doing fine in preschool along with other three, four, and five-year-olds and excels at fine motor skills, even being able to write her name before she was three.

"I was so worried about so many developmental things with her, I forgot what it is like to have a three-year-old. She is getting very bold and feisty," said Melissa.

"She loves to play with her brother (Dylan, 7) and sister (Delaney, 10). She loves to sing and dance and has participated in her first dance recital. She is really catching up for lost time."

Melissa offered encouragement for other parents who are dealing with their child's disabilities. "We know how blessed we are and how complicated things can be with hypotonia. When Demi was born, we had nobody to look to or talk to; all this was new to us. We hope Demi's story can touch others and give them hope too. It's been a wonderful experience.

Never anything I would have signed up for, but it has made us all better, different people now."

The family knows the future will be bright for Demi. Said Melissa: "The sky is the limit as far as we're concerned."



### Patient Care Centers:

1737 State Street, Schenectady, NY 12304

400 Patroon Creek Boulevard, Suite 106, Albany, NY 12206

5010 State Highway 30, Suite 104, Amsterdam, NY 12010

17 Main Street, Queensbury, NY 12804

290 Church Street, Saratoga Springs, NY 12866

Main Telephone (518) 374-6011

or (800) 774-9824

Fax: (518) 393-3292

www.sampsons.com