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## MaLea Fox: Tracking Milestones

■ By Laura Fonda Hochnadel

### Sit Before You Stand

**Like most mothers, Ashley Graber tracks her daughter's developmental milestones,** and at seven-and-a-half months of age, MaLea Fox was on track. "She was just starting to get up on all fours and do the rocking motion of wanting to crawl," Graber says. "She was rolling around, sitting up on her own, and just starting to babble. She was happy." She still is a happy baby, Graber says, despite everything. "Everything" being bilateral transfemoral amputations, extensive nerve and muscle damage to her right arm, numerous skin grafts and surgeries, needles, breathing and feeding tubes, being poked and prodded, and handled and hospitalized for months—all as a result of contracting meningococemia last summer.

On June 11, 2011, MaLea watched as her big sister Shyann opened birthday presents and blew out candles on her birthday cake. While at the party, she shared a bowl of ice cream with her aunt and played with her sister and cousins. Twenty-four hours later, she was hospitalized with meningococemia, and physicians weren't sure if she would make it through the night.

"Normally when she wakes up she is really happy and ready to go and wants to play, and that morning she woke up and was really cranky..." Graber recalls. "So I took her temperature and it was 102.4 degrees."

Graber took MaLea to a local hospital and despite tests, a chest x-ray, and an ultrasound, the physician couldn't find anything wrong. Graber was sent home with instructions to give MaLea Children's Tylenol and to return if her fever worsened. MaLea awoke from a nap later that afternoon with a bruise-like rash on her lower abdomen, and Graber immediately suspected meningitis; she says that she recognized the rash from a months'-old Google search. This time, Graber took MaLea to Columbia Memorial Hospital (CMH), Astoria, Oregon; by then the rash had spread up her torso. The emergency room physician suspected meningococemia. She contacted on-call pediatrician Katrina McPherson, MD, who rushed in and set up the necessary equipment to consult with Jennifer Needle, MD, MPH, via the Oregon Health & Science University (OHSU), Portland, Telemedicine Network, which allows community hospitals to consult with OHSU specialists using a secure, two-way audio-video communications system. Under Needle's supervision from 100 miles away, McPherson started treatment immediately that was instrumental in saving MaLea's life. The infant and her mother were airlifted to Portland later that night, where Needle, a Doernbecher Children's Hospital (Doernbecher) pediatric intensive care specialist, presided over MaLea's care.



MaLea and her mother, Ashley Graber. Photographs courtesy of Oregon Health & Science University/Ken Olsen.

MaLea was hospitalized for 111 days—33 days in Doernbecher's pediatric intensive care unit (PICU), 67 days in Doernbecher's general pediatric unit, and 11 days at Shriners Hospital for Children-Portland. She was discharged on October 1.

"They did an amazing job treating my baby and making her healthy again," Graber says.

While MaLea has had some setbacks because of her illness, Graber says it gives her all the more reason to continue tracking and applauding MaLea's developments: learning to sit up with pillows propped behind her last October; sitting independently in December; and scooting around in circles on her butt—the momentum of which gradually moves her from her original position and entices her to continue. On January 24, the then 13-month old stood for the first time—on stubbies—with her mother's assistance and the use of a walker. Within two days MaLea was able to stand in her stubbies with her walker for ten unassisted seconds, a feat that she repeated the following day. MaLea's upward trajectory continues and brings new accomplishments each week—a miracle, given what she's been through.

### Stand Before You Walk

It might take a village to teach a child, and it definitely takes a village to heal a child. MaLea's "village" includes nurses, physicians, surgeons, and medical specialists of all types. The latest additions are physical and occupational therapists and a prosthetist.



MaLea attends twice-weekly occupational and physical therapy sessions, with a rehabilitation team that Graber says is awesome, although MaLea might beg to differ. “[MaLea] hated rehab because they made her work,” Graber says. “She hates her physical therapy. She hates her occupational therapy. I can’t blame her...; [she] doesn’t understand.”

Therapists work with MaLea to strengthen her muscles, improve her flexibility, establish her independence relative to similarly aged toddlers, expand her vocabulary, and get her mobile—with and without her stubbies. She now scoots forward, rather than just in circles, with little to no assistance. “She just started... trying to move herself forward without holding on to my hands,” Graber says. MaLea has also learned to move her affected arm out of the way and roll onto her belly, and she tries to get up on all fours. Her vocabulary continues to expand; she now says “hi” and “bye” and her therapists are trying to teach her to say “ball” and “bear.”

Though MaLea was reluctant to don her stubbies, “she actually did very well with [them]” says MaLea’s prosthetist, Todd DeWees, CPO, Shriners Hospital for Children-Portland, of her first time standing. “She wasn’t excited about it...but as soon as we kind of got her [standing], the tears dried and she perked up.”

The protocol for acclimating MaLea to her stubbies requires two to three 30-minute sessions a day of her standing at the walker, couch, or any toy of similar height. “Once you get her standing and she realizes that she can play while standing then



MaLea has extensive scarring, which Todd DeWees (left) had to take into consideration when he fit her with liners and sockets.

she is happy...,” Graber says. “She is a trouper and just pushes through it.”

## Walk Before You Run

DeWees anticipates that by the time MaLea ages out of the Shriners system, he will have fitted her with 15 to 18 sockets per leg. He says it will give the Shriners O&P staff a long time to develop a relationship, know what MaLea’s needs are, and help her through the prosthetic-related transitions. At this point, given how well she took to her stubbies, DeWees says he believes MaLea will soon advance to “furniture cruising” and supported walking. Once she can walk in her stubbies with minimal assistance, she will be transitioned to devices with feet and walking knees, which will give her a bit of height and allow her to bend her knees while sitting. And, if she progresses as anticipated, MaLea will be transitioned to full functioning knees by age five or six.

When not undergoing therapy, MaLea is your typical toddler. She is entranced by toys that have lights and sounds, Graber says. Her face lights up and her mood elevates any time she hears or watches the *Little Einsteins* cartoon, and she loves to dance with her most favorite person in the world—Shyann. “I’ll get on my knees and I’ll set MaLea on my chest so she is eye level with her sister and I move around so MaLea thinks that she is moving and they dance together,” Graber says. “MaLea loves it... No one can make her laugh like her sister.”

MaLea will go to school. She will make friends. She might play sports, and she might take dance lessons or music lessons. She will fall and have to dust herself off and get up—just like any child. DeWees says that in his five years at Shriners he has treated children with similar and higher levels of amputation who are not only functional but excel in all sorts of activities, and thus sees MaLea’s limitations “being those she places on herself or those that others around her place on her.”

Graber agrees. “MaLea can and will do ‘normal things,’ and I don’t ever want to limit her.” **O&P EDGE**

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With therapy and practice, MaLea continues to progress with her stubbies.