

## Lab Assistant Helps Secure New Law

Tracy Parlier never thought medical equipment would replace a kitchen table in her modest ranch home in Galesburg. She never thought she would be on a first-name basis with a state legislator. And Parlier never thought her boss, OSF HealthCare St. Mary Medical Center President Jennifer Junis, would take multiple plunges into a dunk tank to support her.

All of those realities came to pass when Parlier, a lab assistant at OSF St. Mary Medical Center in Galesburg, found herself questioning her then-infant daughter Lily's inability to sit up at five months. Lily was born prematurely and had other health complications, so it took 11 months before she was diagnosed with type II spinal muscular atrophy (SMA) in June of 2016. The disease is a form of muscular dystrophy and it's the number one genetic cause of death for infants. The disease has affected Lily's ability to walk so she needs a wheelchair. She has a machine to make her coughs more productive and she has trouble eating, so most of her nutrition is delivered via a port in her stomach, although she occasionally eats a little of her favorites – French fries and popcorn chicken.

Despite the devastating diagnosis, hope arrived at the beginning of the year when the federal government approved a drug called Spinraza, the first and only drug to date for treatment of SMA. The drug is administered by removing five milliliters of spinal fluid and injecting the same amount of the medication. Parlier says when administered early, even for babies with the most severe form of SMA, the drug can greatly improve quality of life and chance for survival.

“With early treatment, they're walking, they're talking. They still have SMA but they have a childhood they would never have had otherwise. As a mom, I can't even explain to you what that would mean – the difference,” Parlier said choking back tears as a feisty Lily squirms, giggles and smiles while sitting next to her mom on the couch.

In July, U.S. Health and Human Services Secretary Alex Azar officially approved adding SMA to the official federal recommendations for newborn screening. But, individual states need to pass their own legislation to require the testing within the first 12 months of life. Tracy and Randy Parlier enlisted help from state Rep. Dan Swanson (R-Alpha) whom they connected with through a family friend. The Parliers traveled twice to Springfield to testify. Swanson says their testimony put a face on the disease and helped lawmakers understand the impact of early screening.

“Lily had the whole room just in awe when she grabbed the microphone and started talking into the microphone. It was pretty amazing,” according to Swanson who joked Lily has a future in broadcasting.

University of Illinois College of Medicine at Peoria Genetic Counselor Jennifer Burton worked with the Parliers as they sought to confirm a diagnosis for Lily. Burton is also on the Illinois Department of Public Health's Newborn Screening Disorder Panel and says the legislation the governor signed in August, to require the newborn testing for SMA by 2020, will make a significant difference.

“Our hope is to catch those babies at birth with newborn screening and start treatment younger, before they even have symptoms and hope that that will greatly improve their quality of life, reduce complications and of course extend survival.”

Swanson vows to continue to raise awareness and plans to ask the Illinois Medical Society to educate members about the disease which affects one in 10,000 children in the US. It's estimated one in 50

Americans are carriers. Swanson plans during the next legislative session to introduce a bill to designate August in Illinois as Spinal Muscular Atrophy Awareness Month. Recently the Parliers received recognition and a similar designation from Galesburg Mayor John Pritchard.

Parlier said the support has been overwhelming, especially from what she calls her OSF HealthCare family.

“Every Mission Partner is praying for us and supporting us. It just means so much,” said Parlier.

Representative Swanson has also been impressed the support from OSF HealthCare.

“Speaking in front of committees, your employer has to support that. OSF has been there to do that. As she mentioned earlier, the support of the team that she’s a part of – to be there to pick up when she can’t be there – to pick up the workload is tremendous,” observed Swanson.

Mission Partners (employees) have attended trivia nights and hosted mini fundraisers. One Mission Partner is designing and building a new bedframe for the Parlier’s eight year-old son Evan to make it easier for Lily to hold and stand while the two play together. Another raised money to get glow-in-the-dark wheels for Lily’s wheelchair.

Adam Peterson, a kindergarten teacher in Morris, IL, is the son of a Mission Partner who works with Tracy. His class adopted the Parliers for Christmas and last year created a book called, “All The Same Yet Totally Different” which he began selling last month on Amazon.com. [In this Youtube video](#), Peterson explains the project and how proceeds will support Cure SMA, an organization supporting research and advocacy.

Peterson was at the August 19 Quad City River Bandits baseball game where Lily was allowed to throw out the first pitch and where OSF HealthCare St. Mary Medical Center President Jennifer Junis agreed to spend some time in a dunk tank for the “Raise Awareness for SMA” promotion.

“I think every 12 year-old boy in the ballpark wanted to come and get a dollar baseball and dunk me. I was a little sore the next day,” Junis shared while noting she didn’t hesitate to say ‘yes’ when Parlier asked her to participate.

Junis is a baseball fan and spent many days at the ballpark because her son grew up loving baseball and now plays professionally for the Kansas City Royals. But, she agreed to subject herself to multiple soggy submersions because she says OSF HealthCare’s culture promotes Mission Partners getting involved in their communities and supporting co-workers.

“Their stories are so powerful and when they tell their stories and really advocate for something, it’s for the greater good. It’s really what our Mission is about – serving others.”

The larger Galesburg area has also rallied around Lily Parlier, with many posts on her Longevity for Lily Facebook page. Most recently, Galesburg Firefighters, including T.J. Scott, used the energetic three year-old as their inspiration to endure brutal heat and humidity while collecting donations at major street intersections for their annual “Fill the Boot” campaign, which supports research and a summer camp for kids with all forms of Muscular Dystrophy. Scott enjoys Lily’s regular visits at the firehouse and he’s hopeful continued treatments will help her continue to be the bouncy little girl who loves life.

“Since she’s gotten those injections she has gotten a lot stronger so we just keeping hoping she’ll get stronger and stronger, don’t we?,” he asked Lily as he took a break from the boot collections to say hello to his little inspiration.

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