

## BROADCAST-Newborn Screening for Spinal Muscular Atrophy Begins This Month

### *OSF Lab Assistant's Testimony Supported New Law*

A new law that took effect in Illinois at the start of this month will likely save lives and it'll make for a better life for infants who otherwise might not receive early treatment that can have a lifelong impact on their development.

The law adds [Spinal Muscular Atrophy](#) (SMA) to Illinois' infant screening program which means every baby born in the state will be tested for the neurodegenerative disease. Illinois and Michigan along with 29 other states now screen for SMA which impacts muscles used for breathing, crawling, and walking. Early treatment can slow disease progression and improve quality of life.

Tracy Parlier and her five year-old daughter Lily were the inspiration behind the Illinois law. 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. It took 11 months before she was diagnosed with type II spinal muscular atrophy (SMA) in June of 2016.

Lily is treated with a drug called Spinraza, that when administered early – even for babies with the most severe form of SMA – can greatly improve quality of life and chance for survival.

### **SOT-Tracy Parlier, OSF Lab Assistant and Mother of a Girl with Spinal Muscular Atrophy (SMA)**

**“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.”**

Tracy and Randy Parlier enlisted help from state Rep. Dan Swanson (R-Alpha) to lobby for Illinois' testing law. 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.

### **SOT- IL Rep. Dan Swanson (R-Alpha)**

**“Lily had the whole room just in awe when she grabbed the microphone and started talking into the microphone. It was pretty amazing.”**

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 will make a significant difference.

### **SOT-University of Illinois College of Medicine at Peoria Genetic Counselor Jennifer Burton**

**“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 has asked 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.

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

### **SOT-Tracy Parlier, OSF Lab Assistant and Mother of a Girl with Spinal Muscular Atrophy (SMA)**

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

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

### **SOT- IL Rep. Dan Swanson (R-Alpha)**

**“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.”**

Mission Partners (employees) have attended trivia nights and hosted mini fundraisers. One Mission Partner designed and built 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.

Former 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. (Junis is now senior vice president for OSF St. Gabriel Digital Health).

Junis 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.

**SOT-Jennifer Junis, Former OSF St. Mary Medical Center President now Senior Vice President of OSF St. Gabriel Digital Health**

**"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](#). If the FDA approves a new drug, as expected next month, the family hopes to transition Lily to a new, easier-to-administer drug [Risdiplam](#) in December.