

Interview Highlights from Tracy Parlier

Why is early detection for Spinal Muscular Atrophy so important?

“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 because they didn’t want others to go through what they had in trying to get a diagnosis.

You’ve received a lot of community support. How has your OSF HealthCare family supported you?

“Every Mission Partner is praying for us and supporting us. It just means so much.” Parlier explained many other ways in which OSF Mission Partners helped her, including the then-president of OSF HealthCare St. Mary Medical Center President Jennifer Junis who attended a River Bandits baseball game in 2018 and raised money by agreeing to go into a dunk tank. Junis said that’s all part of the culture at OSF HealthCare which has a Mission of serving with the greatest care and love.

“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,” according to Junis.

Interview Highlights from University of Illinois College of Medicine at Peoria Genetic Counselor Jennifer Burton

How did you get involved with the Parliers and the push for SMA screening for newborns?

I am on the Illinois Department of Public Health screening board which helps decide whether it is appropriate to add a disease or condition to the required screening. After meeting the Parliers and seeing how long it took for them to get the right diagnosis, it seemed right to bring SMA to the rest of the review panel.

“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.”

Interview Highlights from State Rep. Dan Swanson

Representative Swanson, you have been involved in several health-related pieces of legislation and you’ve had others testify in Springfield on behalf of the bill. How was Tracy and Lily Parlier’s appearance so impactful?

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

Swanson has successfully passed legislation related to Lyme disease in Illinois. He said traveling to Springfield and testifying can be a terrifying experience so he really applauds Tracy and the whole family.

Were you impressed by the level of support given to Tracy and her family by 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.”