

March 7, 2012

Testimony

Public Health Committee

Support for Raised Bill Number 56

An Act Concerning Pulse Oximetry Screening for Newborn Infants

Submitted by Kelly Morrissey, a resident of Southington, CT

As a mother with a daughter diagnosed with Tricuspid Atresia, a critical congenital heart disease (CCHD) and a volunteer advocate for the American Heart Association, I am writing in support of S.B. 56 'An Act Concerning Pulse Oximetry Screening for Newborn Infants.'

I would like to thank Senator Gerratana and Representative Ritter for raising this incredibly important legislation. I urge the committee to vote S.B 56 out of committee and work to ensure this lifesaving bill reaches the governor's desk for his signature. I believe my daughter's brave story will help make clear why early detection of CCHD is so critical.

Alice was born June 7, 2011 at Hartford Hospital weighing 6 lbs. 3oz, 19 ½ in. long. Due to Alice's known heart defect she was taken to the Neonatal Intensive Care Unit (NICU) where her heart would be evaluated. Her team of cardiologists evaluated her for three days during which time she was connected to a constant pulse oximeter. It was determined that the Atrial Septal Defect was sufficient for Alice and would be sufficient until it was time for the Glen Shunt Procedure. Alice's oxygen levels were in the high 80's, excellent for someone with her type of heart defect

My husband Paul and I brought Alice home from the hospital on June 9, 2011. We were excited about going home, introducing Alice to our dog Rufus, her great grandmother Julia, her grandparents and her aunts and uncles. We were nervous, not because of her heart defect because looking back we had no idea what extreme trauma and life altering moments we would soon have. No, we were first time parents so we worried about "doing things right".

For 10 days we worried about "doing things right". Then we had one of those days you never forget, a day we call black Monday.

Paul and I took Alice to her scheduled follow up appointment. She was tested with a pulse oximeter, and it was found that her oxygen levels had dropped to dangerous levels, her readings varied from 70's to the low 60's. These readings were far below safe. With oxygen levels this low she could suffer from brain damage. Alice was immediately taken to the intensive care unit, where things began to move very fast. Alice was Med Flighted that day to Boston Children's Medical Center, where she underwent emergency open heart surgery. Because of swelling and excess liquid, it was not immediately clear if the surgery was successful.

Within days of the first surgery, Doctors determined the shunt Alice received was too big and they would need to perform a second open heart surgery to clip the shunt making it smaller to match her tiny body. When it was time to leave the hospital our doctors told us some sobering facts. If we had not had that routine cardiologist appointment, if they had not insisted on an accurate pulse oximeter reading, if they

had not intubated, if they had not Med Flighted Alice, if the amazing team of doctors had not done everything they did in the exact order in which they did it, we would have lost our Alice.

Congenital heart defects are the number one killer of infants with birth defects. Congenital heart defects are structural abnormalities of the heart that are present at birth. These defects range in severity from simple holes or murmurs to severe malformations, such as the complete absence of one or more chambers or valves. Some critical congenital heart defects can cause severe and life-threatening symptoms that require intervention within the first days of life. Pulse oximetry testing before discharge may be one important strategy that can be an effective, noninvasive, inexpensive tool to assist in diagnosing critical congenital heart disease.

Paul and I understand firsthand how important it is to identify CCHD as soon as possible.

This committee can help our young ones live longer and fuller lives by passing S.B. 56 to pinpoint critical or possibly life-threatening heart conditions that might otherwise be missed. This simple, non-invasive test could significantly improve the outcomes for hundreds of Connecticut's babies born with heart defects.

I encourage you to help give our children a healthy start in life by assuring newborns are screened for congenital heart defects using pulse oximetry. So many young lives depend on it.

Thank you.