

**Testimony Submitted to the
Secretary's Advisory Committee on Heritable Disorders
in Newborns and Children**

By

Assemblyman Jason O'Donnell

Member, New Jersey State Assembly, 31st Legislative District

At the

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My name is Jason O'Donnell, and I serve as an Assemblyman for the 31st Legislative District in the Great State of New Jersey. I have the privilege of submitting these comments to you today not only as a legislator who has proposed a bill to mandate pulse oximetry testing in the state of New Jersey, but also as a father of a son who survived Congenital Heart Disease. As you can tell, this issue is near and dear to my heart. But more importantly – it just makes sense. In 2011, in the greatest nation on earth, there is simply no excuse for newborn children dying because a small, non-invasive test that costs less than \$10.00 has not been utilized to check for heart defects. Thank you, in advance, for considering my comments.

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In the Fall of 2010 I was fortunate enough to be selected to fill a vacancy in the General Assembly, and subsequently won the special election for that office. I am a career firefighter – I hadn't considered running for public office. Before running for office, my wife and I discussed what this would mean for our family, and the time it would take away from her and our three children, Caroline, 8, Jack, 6, and Patrick, 4. WE decided that I should accept the opportunity and do my best to make a difference.

New Jersey's Pulse Oximetry Bill, A-3744

One of the first pieces of legislation I introduced was Bill A-3744, requiring that a pulse oximetry test be performed on every newborn in New Jersey who is at least 24 hours of age. I am happy to report that

this bill passed unanimously in both the General Assembly and the State Senate, and is now awaiting our Governor's signature.

Understand, please, that in the state of New Jersey, we conduct 54 tests on newborns. None of those tests screen for heart defects. We have a mandatory check for hearing on newborns, yet we don't have a mandatory check for life-threatening heart defects. We lose at least 3-4 children a month due to undetected CHD. That's four children a month, four mothers a month, four families a month whose lives will never be the same. With all due respect, a child who has a hearing problem still can live a healthy life. A child who has a heart defect could die within days or years – and too many children certainly have met this fate.

Concerns

Most people were supportive of my bill, but there are those who expressed their doubts.

Accuracy of the pulse ox test was brought into question. Studies have shown that when pulse ox is done at least 24 hours after birth, the false positive rate falls drastically. No test is perfect, so there may still be an occasional false positive. So what does this trigger? Another simple test to ensure that the child's heart is healthy. At the end of the day, a few more hours of testing – and perhaps even a few more hours of parental worrying – is well worth the resolution that those parents will feel knowing their baby does not have congenital heart disease.

Some expressed concerns over cost. The cost of a pulse ox test is less than \$10.00. A hospital diaper change costs more than a pulse ox test. Additionally, the precaution from performing the test will prevent the costs of emergency services should the baby have gone home and gone into heart failure. It will help prevent potential organ damage, potential neurological impairment and developmental delay because of an undetected heart defect. In reality, it will also prevent malpractice lawsuits against doctors and hospitals.

Still, others expressed concerns over not knowing enough about the test, asking for more research and more time to consider the matter. There have been studies conducted for the more than a decade, with several just published in the past two years.. The Secretary's Advisory Committee on Heritable Disorders (SACHDNC) in Newborns and Children working with the American Academy of Pediatrics, the American College of Cardiology, the American Heart Association, and other stakeholders to establish standardized federal recommendations for screening and diagnostic follow-up of Critical Congenital Heart Disease (CCHD) is the solution.. We do not need more studies, we need action – our children's lives depend upon it.

Personal Experience

My third child was a particularly hard labor for my wife. The pediatrician examined Patrick when he was born, and heard a heart murmur – something extremely common in newborn babies. To our pediatrician's credit, he decided to be extra cautious, and he asked my wife and I if he could bring in a

pediatric cardiologist. The pediatric cardiologist arrived, examined Patrick, and told us our son needed to have surgery immediately.

We were fortunate. We had a very good pediatrician, and a very good cardiologist. My wife and I had decent health insurance plans. We also live in a major metropolitan area, which afforded us many healthcare options for our son's surgery.

In Summation

Will my bill in New Jersey solve all heart issues for all newborns? Of course not. There are still many issues to confront, such as access to health care in rural areas and disparities in quality care and health insurance in lower socio-economic areas. However, this should not deter us from moving forward with actions that will save lives. Pulse Ox is a first step, not a final solution. There is more work to be done.

I hope and pray that New Jersey can help lead the way to saving the lives of newborns with CHD. Our children deserve nothing less than the best healthcare we can afford them. We can afford them this simple, non-invasive, low-cost test. Thank you.