

Testimony of Michelle Lawrence, WRITTEN ONLY
Mother of Nolan Lawrence
HB49 as Introduced by the Governor
House Finance - Health and Human Services Subcommittee
March 23, 2017

Dear Chairman Romanchuck and members of the HHS Subcommittee,

Thank you for the opportunity to provide testimony on the CMH - Children with Medical Handicaps, also known as the "BCMh," program. I am writing to put a face to one of the 40,000 children served by the CMH Program in the Department of Health and ask that you save the CMH Program by protecting it from proposed changes in the Governor's budget.

My husband John and I learned that something was seriously wrong with the development of our child's heart during a routine 20-week anatomy scan, and that our first-born had a Congenital Heart Defect. Five months later we welcomed our son Nolan into the world. His official diagnosis was and is Double Outlet Right Ventricle (DORV) with a large Ventricular Septal Defect (VSD), Transposition of the Great Arteries (TGA) and a mitral valve that straddles over into his left ventricle through the VSD, which is basically a huge hole between the bottom chambers of his heart. Due to the complexity of Nolan's anatomy he is considered "Single Ventricle," and though his prognosis isn't hopeless, there is no way to fully repair his heart. He'll require a lifetime of cardiac observation and care, and potentially need further medical/surgical interventions in the future. When we first met with Nolan's pediatric cardiologist shortly after that initial anatomy scan, he explained to us that our child's best shot at a "normal" life is a series of 3 palliative, open-heart, surgeries that would allow his circulatory system to function with only one working ventricle. So far Nolan, now 2 years old, has had 2 of these surgeries and within the next couple weeks we'll schedule the 3rd, called the Fontan, to take place this May.

Handing Nolan over to the surgical team, be it for open-heart or cardiac catheterization procedures, is indescribably challenging. Thankfully, our little heart warrior has always pulled through and recovered quickly. However, it never fails that once our son is given the green light, my mind turns back to our financial situation and I begin once again to fret over our coverage and insurance. Even when we're not dealing with surgery, multiple trips to the Heart Center at Nationwide Children's Hospital for check ups, echocardiograms and EKG's throughout the year quickly add up. My husband and I both happily work for small independently owned businesses here in Columbus, and have private insurance through my employer. We pay for most of our monthly premiums, in addition to high yearly out-of-pocket costs. (B)CMH has become an invaluable safety net for our family, by assisting with the out-of-pocket costs our private insurance does not pick up.

Please allow the Department of Health to continue to provide this extremely important program for chronically ill children like Nolan. The proposed changes seem to dramatically reduce services and eligibility for families like ours. Although the language seems to "grandfather" our family into the CMH Health program, I'm concerned about future generations and our future eligibility. My family is a cost-share family and the proposed change to move the program into Medicaid will mean that we may no longer meet the financial eligibility guidelines.

In 2017, our total monthly insurance premiums combined with our maximum out of pocket expenses will cost over 20% of our yearly household income. Just based off of Nolan's individual out-of-pocket cost alone, CMH Program assistance saves us about 5% in medical expenditures. It may not sound like a great deal, but every bit of assistance we receive makes a substantial difference to our family, especially since we own our own home (and always seem to be fixing one thing or the other) and have another baby boy on the way. I've heard too many real-life scenarios regarding parents in similar situations who encountered some private insurance nightmare, had to quit their jobs and dissolve their modest assets to obtain Medicaid in order to ensure their children receive the healthcare they need to survive.

The (B)CMH program has had great success for almost 100 years, providing assistance through the medical home model and keeping families like ours privately insured, contributing to our local economy, paying our taxes and owning our homes. I am extremely concerned that CMH children like my son will fall through the cracks if the program is moved from the Department of Health to the Department of Medicaid.

Thank you for protecting Ohio's children by allowing the CMH program to continue providing services to middle- and low-income families, and many thanks for the opportunity to share my family's story. Please do not hesitate to reach out with any questions. I'm happy to be of assistance.

Kind Regards,

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