

Testimony before House Finance Committee
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Presented by Margaret Demko, parent

I am a parent of a three year old little girl with Down Syndrome. We live in Athens County. Emily has been uninsured for almost one full year.

Margaret J Demko
1948 Mill Street
Albany, Ohio 45710
740-698-1315
740-818-8460
margaretdemko@gmail.com

Good morning Chairman Hottinger, Ranking Member Skindell, and members of the House Finance Committee. My name is Margaret Demko, and this is my daughter, Emily. She is 3 years old and has Down Syndrome, a genetic condition occurring in one in every 800 live births. We are from Athens County, and I am a very active parent, taking roles in the ARC of Ohio as president of our local chapter and serving as a member of our local Board of MRDD. I am here today to tell you our story and how waiting for healthcare coverage is still impacting Emily's future.

When Emily was born, I was a full time working person who had creditable healthcare coverage. Once we received her diagnosis and realized that there were many issues that needed to be met on a daily basis, our family decided to have me stay home and my husband continue his work as a self employed contractor. We suddenly were without healthcare coverage. I looked into many options, but no private insurer would cover Emily, at any cost, due to her genetic, pre-existing condition. When I turned to Medicaid, we qualified, but only by a few dollars. Emily began physical, occupational and speech therapies immediately, and the effects of these professional services were outstanding. She was testing at or just a few months below her chronological age, she walked before she was 2, and did many other skills that a child with Down Syndrome may not ever accomplish.

During our 6 month reauthorization meeting, I was told that our income was \$135.00 per month too much to allow her to qualify for Healthy Start. That very same month, we had medical bills for her in excess of \$3500. As a

family in the 250-300% of poverty level, these bills were devastating. We had to make decisions about her therapies, and ultimately, she has been reduced to 20 minutes of professional speech therapy a week, dropping our bills to a little over \$450.00 per month. This isn't nearly enough to help her skills grow and become a fully participating member of society.

While she continues to amaze her doctors and therapist, and is not showing any signs of regression, there are other worries beyond therapeutic ones. She has recently developed issues with her feet and ankles. She is turning her feet inward and walking on her instep, a condition that can be corrected by expensive orthotic inserts for her shoes. However, for her to have these, we would have to then pay for physical therapy for her to learn to walk with them at the cost of over \$100.00 per hour session. She is also in need of hearing tests, corrective treatment for an eye condition, and several blood tests to scan for conditions likely to occur with Down Syndrome. We are going to get all of these for our daughter, but we have to take them one step at a time, and hope that we are not too late to correct any problem that is found. Although I work from home as much as I can, with all of these medical appointments and therapy sessions, it is impossible for me to return to a full-time, full-benefit position. We simply cannot afford, although my husband is very successful, to incur all of these medical expenses at the same time. We have to actually consider if we should miss a mortgage payment or car payment if the medical expenses become too overwhelming.

On behalf of children like my Emily and so many others across our state thank you for supporting the expansion of Medicaid and SCHIP to cover more Ohio children. These programs work. Access to health coverage will help keep Emily healthy and help achieve our goal of her living a healthy, happy productive life, no matter what her disability.

Thank you for the opportunity to share my story in support of the continued efforts of expansion of children's health care coverage. I can answer any questions at this time.