Interested Party Testimony House Sub-Bill 33
Senate Finance
Thursday, March 25, 2023
Randi Clites, Patient Advocate ODH Caregiver Volunteer

Chairman Dolan, Vice Chair Cirino, and Ranking Member Sykes, and members of the Senate Finance Committee, my name is Randi Clites. I am here to testify today in my role as a mom of a young adult with two rare disorders, a parent volunteer on the Children with Medical Handicaps (CMH Program) Parent Advisory Council, and non-profit representative and Chair of the Rare Disease Advisory Council.

I'd like to thank Governor DeWine, and many of you, for your long-time support of the CMH program. As an advocate for the program since 2005, it is a very welcomed proposed name change of the over 100-year-old Title V Program from Children with Medical with Handicaps to the Children and Youth with Special Healthcare Needs - Complex Medical Help Program. I hope you will all support this updated name change to align with many other programs around the country. Ohio's program is one that is leading the way in valuable services to middle-income families facing huge financial and emotional burdens. It is truly a safety net in many ways to Ohioans with children affected by rare and medically complex conditions.

Two things I was very passionate about when I was honored to serve in the 133rd General Assembly; first giving a voice to those families and then protecting their children's access to affordable healthcare. I was extremely grateful for the passage of the bill to establish the Rare Disease Advisory Council and my comments come from the programs our council has been monitoring since our first meeting in May of 2022. We look forward to providing you our first report of our work soon.

In the Redbook for HB 33, there was a reference to HB 110 of the 134th General Assembly, which required the ODH Director to increase the maximum age of CMH participants up to 23 years old with an additional funding increase of 4.9%. In HB110, it was approved that on July 1, of both 2021 and 2022, the age of eligibly for the treatment program of CMH was increased by one year. The final increase, on July 1, 2022, allows individuals under 23 to participate. However, the original legislation requested that the Treatment Program be increased to age 26 to mirror when young adults will age off of their parent's health insurance coverage. Unfortunately, when the House passed sub bill HB33, the language was removed, so I ask for your support of Amendment SC1257, which will increase the age limit up to 26 and fund the increased enrollment to allow those young adults to continue their access to the Treatment Program until they transition off of their parents health insurance coverage.

As was reported at the CMH Parent Advisory Council meeting, the program increase has assisted over 500 young adults 21 years old in the first year. These young adults have overcome many obstacles throughout their young lives managing a complex medical condition and this small program increase will help them become thriving young adults. The funding request will cover this increase of enrollees.

Last General Assembly, in partnership with EveryLife Foundation for Rare Diseases, I helped to lead a patient organization initiative to bring Ohio up to compliance of the recommendations of the Recommended Uniform Screening Panel (RUSP) by adding two conditions Spinal Muscular Atrophy (SMA) and Adrenoleukodystrophy (X-ALD) to Ohio's Newborn Screening Panel and provide a pathway for quicker adoption of RUSP approved conditions. Our workgroup recommendation was to give up to two years to add a condition to Ohio's Newborn Screening Panel, which would allow for Ohio Department of Public Health Lab (440451) to make a request of additional funds in the following budget process.

We were encouraged to see line 440451 had a significant increase (62%) in the Governor's Proposed budget in HB33 and was hopeful that would include supporting the increase funds to add the -now- four conditions needed for federal RUSP alignment.

The RUSP has recently approved two more conditions for recommendation to the State Newborn Screening Panel (MPS II and GAMT,) which will also need additional funding support within the year. They had not recommended another addition since SMA was approved in July 2018 and X-ALD in 2016, so as you can see it is extremely important to support the work of the public lab as more treatments become available for rare conditions the need will grow for testing.

Please support Amendment SC1841 to protect Ohio's newborns and make sure our babies have access to the resources available to surrounding states.

Lastly, thank you for your support of adding Duchenne Muscular Dystrophy to Ohio's Newborn Screening Panel. Ohio is a world leader in research and treatment for DMD, so allowing for this testing in Ohio will be a huge benefit for early diagnosis and treatment options for Ohioans.

Thank you for the opportunity to provide testimony today and I'd be happy to try to answer any questions you may have.