Interested Party Testimony House Bill 33
House Finance Subcommittee on Health and Human Services
Thursday, March 23, 2023
Randi Clites, Patient Advocate ODH Caregiver Volunteer

Chairwoman Carruthers, Ranking Member Liston, and members of the HHS Sub-Committee, my name is Randi Clites. I am here to testify today in my roles as a parent volunteer on the CMH Parent Advisory Council and non-profit representative on the Rare Disease Advisory Council.

First, I'd like to thank Governor DeWine for his 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 Handicaps" to "Children and Youth with Special Healthcare Needs - Complex Medical Help Program".

Also, I'd like to thank Ranking Member Liston for asking the clarifying question to Director Vanderhoff during his testimony last week about the increase in funding to GRF ALI 440505 of 4.9%. It seems from the answer that the Director gave, he believed the Governor's aim of the increase is to carry out the intention of Representatives Liston and Fraizer's HB 212 of the 134th General Assembly, which is to increase the Treatment Program age limit to 26 years old.

In the Redbook, there is a reference to H.B. 110 of the 134th General Assembly which required the ODH Director to increase the maximum age of CMH participants. On July 1, of both 2021 and 2022, the age was increased by one year. The final increase, on July 1, 2022, allows individuals under 23 to participate in the treatment and service coordination components of the program.

As was reported at the CMH Parent Advisory Council meeting, the program increase has assisted over 500 young adults 21-22 years old in the first year. These young adults have overcome many obstacles throughout their young lives dealing with a complex medical condition, and this small program increase will help them to become thriving adults.

I would only ask that a clarifying amendment be submitted that directs ODH to increase the treatment program of CMH to age 26 with the proposed increase of funds.

Lastly as an advocate for the Rare Disease Community, I'd like to request the committee's support for the increased funding on line item 440451 for the ODH Lab. In H.B.110, the legislature gave authority to the State Lab to add two conditions (SMA and X-ALD) to the newborn screening panel, which would align Ohio with the Federal Recommended Uniform Screening Panel (RUSP) and give a direct pathway for newly added RUSP conditions to the Ohio Panel within 2 years. Since the passage of HB 110, two new conditions (MPS II and GAMT) have been added to the RUSP and may be approved for Ohio's panel soon.

I am encouraged by the proposed increase and with increased funds that the lab will be able to provide the much-needed staff and lab support to get Ohioans the critical information needed from the screening results in a timely manner.

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