

Chairman Cirino, Vice Chair Chavez, Ranking Member Hicks-Hudson, and members of the Finance Committee,

I currently serve as the Co-Chair of the Rare Disease Advisory Council (RDAC) and served in the 134th as the Chair. The Ohio RDAC has a strong national presence and has had many opportunities to advise the legislature and administration on policy decisions impacting the Rare Disease Community.

When I asked Representative Ginter to join my efforts in the 133rd GA to introduce a bill to establish the RDAC in Ohio, he would regularly say “this council will not be an in name only work group.” I have worked very hard to make sure our Ohio RDAC is a strong group of advocates willing to put in the work to advise on important matters affecting Ohioans.

It is with great respect that I ask for the proposed abolishment of the council to be removed from the Senate Version of SubHB96 and allow the Ohio RDAC to continue to be a national leader in this space.

Below is the list of the appointed members and the report that I submitted after our first GA; the second report is being provided at the next quarterly meeting in August. We have met with quorum every quarter (except one meeting that was canceled because of weather,) since this report was provided to the Governor and Leadership of the House and Senate.

Senator Steve Huffman

Senator Hearcel Craig

Representative Beth Liston

Ms. Jennifer Voit

Ms. Kathleen L. Barrett

Ms. Annie Ross-Womack

Ms. Kelly Maynard

Ms. Kimberly Wallis

Ms. Randi L. Clites

Ms. Shelia L. Hiddleston

Ms. Tiffany N. Sammons

Ms. December West

Mr. Joshua J. Hahn

Dr. Kandamurugu Manickam

Dr. Loren D. M. Pena

Ms. Eileen Sullivan

Dr. Sanjay P. Ahuja

Dr. Terri M. Moncrief
Ms. Anne Clark
Mr. C. Daniel Bradford
Mr. Patrick Londergan
Ms. Amista N. Lipot
Ms. Andrea E. Hoffman
Mr. Edward Pauline
Ms. Angela L. Snyder
Ms. Gretchen Blazer Thompson

The RDAC held its first meeting virtually on March 10, 2022 and met an additional four times in the 134th GA.

Summary of the meetings:

March 10, 2022 – Virtual Meeting / Quorum Established

The first meeting consisted of brief introductions including experience in rare disease by all members. ODH Staff provided a review of the Council information regarding RDAC. Each nonprofit representative provided a presentation of their work. Randi Clites was elected as Chair of the RDAC. Had a discussion about breaking into subgroups and what the subgroups should be.

May 5, 2022 – Virtual Meeting / Quorum Established

Three patient representatives gave presentations on diagnosis and access journey. Council formed three subcommittees and named leads:

Research – Leads Dr. Pena and Dr. Kopp

Diagnosis – Leads Dr. Manickam and Eileen Sullivan

Treatment – Kelly Maynard and Tiffany Sammons.

ODH provided information about the Children with Medical Handicaps program.

June 23, 2022 – Virtual Meeting / Quorum Established

Three patient representatives gave presentations on diagnosis and access journey. Discussion led to the interest from the RDAC of the provider perspective to be the next presentation to RDAC. Plans were made to review other state RDAC for report ideas.

September 22, 2022 – Riffe Center / Quorum Established

Questions were discussed about appointments for the next GA and process for reappointments. No member presentations were given. Members shared overall concerns for patients with rare disease in Ohio. Items shared: More awareness needed, pain

management, need for specialized training, pipeline treatments, and need for assistance to access out of state care. Discussion of what Ohio RDAC website should have available. ODH Legal covered the statutory authority of the RDAC.

December 8, 2022 - State of Ohio Library / Quorum Established

RDAC provided overview of the appointment process for the 135th GA. Discussed ways of providing the two reports outlined in the ORC. Member presentation on development of new rare disease therapies. RDAC Website was introduced to members for feedback. Plans were made to raise awareness for Rare Disease Day on February 28, 2023. 2023 calendar was set. Meetings to be held: February 2, May 4, August 3 and November 2.

Accomplishments:

The RDAC formed three subgroups, Research, Diagnosis and Treatment, with a goal of preparing a report next general assembly to detail the following:

The coordination of statewide efforts for studying the incidence of rare diseases in this state; Findings and recommendations regarding rare diseases in Ohio;

Efforts to promote collaboration among rare disease organizations, clinicians, academic research institutions, and the general assembly to better understand the incidence of rare diseases in Ohio.

The Ohio Department of Health provided a landing page on the ODH website for the RDAC to share meeting notices, agendas, and minutes. All meetings of the RDAC were completed with a quorum.

The RDAC appreciates Governor DeWine, the Department of Health, and Legislature's efforts in soliciting nominations of qualified candidates and communicating with the Ohio Boards and Commissions to ensure a fully functioning Council.

Respectfully submitted,

Randi Clites

Rare Disease Advisory Council 135th GA Co-Chair