

Dear Chair Cirino, Vice-Chair Chavez, Ranking Member Hicks-Hudson, members of the Senate Finance Committee.

My name is Murugu Manickam, MD and I am a clinical geneticist/physician in practice for the past 16 years. I am the co-chair of the Ohio Governor's Rare Disease Advisory Committee and have been a member of the committee since its inception in 2022. My primary medical focus is on those with rare disorders, individually disorders that affect less than 200,000 Americans; however cumulatively, 1:80 individuals are diagnosed with a rare disorder in the US encompassing more than 2000 different disorders. What brings these patients/families/advocates together is that rare disorders are different from "common disorders" in that most people, let alone physicians, are not well-versed in these disorders and their care is different. Rare disorders affect every community, every social economic class, every race/ancestry/ethnicity and all ages, though many of these disorders are also life-limiting.

I am writing to you today to request the committee remove a new proposal within the Senate version of HB96 to abolish the Rare Disease Advisory Council.

The Ohio RDAC was established in the 133th General Assembly. I was nominated for the group as a representative for the Hospitals Association and because of my work in rare disorders- I am the first author on national guidelines for the use of gene testing to diagnose rare conditions. The first meeting for the Ohio RDAC was held in March 2022 and has met quorum at every meeting held quarterly since (with one meeting canceled because of the weather). The RDAC has up to 31 members who voluntarily and represent many communities across Ohio as well as many disciplines, from medical providers to patient advocates to researchers to business interests in the state. The council works to advise and educate both lawmakers and administration on issues impacting the Rare Disease Community in Ohio.

Ohio has been a national leader in rare disease because of public-private collaborations. Several treatments were developed first in Ohio through these public-private enterprises including treatment for Spinal Muscular Atrophy- previously this was a fatal disease in early childhood. The gene therapy for SMA was developed at Nationwide Children's Hospital, licensed to a pharmaceutical company and now available across the world to save these children's lives. Ohio was also one of the first states to develop the newborn screen for SMA which identifies this rare disorder before symptoms occur and allows for children to thrive and not just survive. The RDAC was designed to help facilitate these public-private collaborations and educate legislators about policies that not only affect Ohioans but by the example of SMA, affect the world.

I would respectfully urge the Committee to eliminate the provision language repealing the Ohio RDAC.

Please feel free to reach out to me for any additional information.

Sincerely,



Murugu Manickam, MD, MPH, FACMG

