June 4, 2025

Ohio RDAC Testimony:

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

My name is Jessica Myers and I am a patient diagnosed with a rare blood disorder called Hereditary Angioedema (HAE). I also work as the Communications and Advocacy Manager for the US Hereditary Angioedema Association (HAEA). I was diagnosed with HAE when I was 15 years old. HAE is a rare, severe, and potentially life-threatening genetic condition. HAE symptoms include recurrent, painful, and disabling episodes of swelling in all body parts including the abdomen. Throat swelling can close the airway and cause death by asphyxiation. While minor trauma or stress may trigger an attack, swelling often occurs without a known trigger. When I was first diagnosed with this condition, I was missing so much school that they weren't sure I would be able to graduate with my peers. However, due to the support I was given by my community and the continued access I have to my lifesaving medication, I now live a life dedicated to giving back to the rare disease community.

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

The Ohio RDAC was estabilish in the 133th GA and the first meeting was held in March of 2022. Ever since, the RDAC has met quorum at every quarterly meeting (with the exception of one meeting cancelled due to weather). There are up to 31 members on the RDAC and they are not paid to be a part of the council. RDAC meetings offer space for patients, healthcare professionals, and advocacy leaders to advise and educate lawmakers on pressing issues related to rare disease in Ohio. These issues can range from investments in research, to access issues to medications like step therapy, prior authorizations, copay accumulators, and state medicaid programs. While these may be familiar issues to legislators, there is a certain amount of nuance that can only be understood through the lived experience of these policies that makes the expertise of the RDAC so essential. Rare disease communities have to fight to preserve coverage and access to innovative care and treatment and without the voice of the Ohio RDAC, our path forward will be made much harder.

As a member of the rare disease community and hopeful advocate, I ask you to allow the important work of the RDAC to continue.

Best,
Jessica Myers