



## Ohio Chapter

### Ohio Chapter

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June 3<sup>rd</sup>, 2020

The Honorable Dave Burke  
Chairman, Health, Human Services, and Medicaid Committee  
Ohio Senate  
Columbus, Ohio 43215

Dear Chairman Burke and Members of the Senate Health, Human Services, and Medicaid Committee—

On behalf of the 2,900 members of the Ohio Chapter of the American Academy of Pediatrics, I am writing today to express our support for House Bill 412, sponsored by State Representatives Clites and Ginter.

As you know, this legislation would establish the Rare Disease Advisory Council under the Ohio Department of Health (ODH). This group of advocates and experts would provide recommendations to the General Assembly regarding the needs of patients with a rare disease.

Additionally, HB 412 requires ODH to publish reports on the incidence of rare disease in Ohio. This is critical data for healthcare providers and researchers to utilize in the treatment of patients.

Children living with a rare disease have unique needs and challenges. The Rare Disease Advisory Council will provide pediatric healthcare providers with a venue to discuss these issues and develop comprehensive solutions and policy recommendations.

It is my hope that the committee will favorably report HB 412 in the near future. Thank you for your consideration of this important legislation.

Sincerely,

A handwritten signature in black ink, appearing to read "Melissa Wervey Arnold".

Melissa Wervey Arnold  
Chief Executive Officer  
Ohio Chapter of the American Academy of Pediatrics