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133rd General Assembly

Sponsor Testimony for House Bill 412
House Health Committee
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Chairman Lipps, Vice Chair Manning, Ranking Member Boyd and members of the House Health Committee, thank you for allowing me to come before you today and present sponsor testimony on House Bill 412. I am honored to be a joint sponsor on this bill along with Representative Clites. Representative Clites has given invaluable insight and has worked diligently to spread the awareness of these rare diseases.

Today there are 7,000 known rare diseases and it is estimated that 1 in 10 Americans live with a rare disease. In the U.S., only a few are tracked after diagnosis and because most rare diseases are not tracked, the exact number or how many people affected is difficult to determine. The price of rare-condition medications has risen 54% in the last 4 years and children represent the majority of those affected. Currently, 90% of rare diseases still do not have treatment options.

The Rare Disease Advisory Council will help address the unique challenges rare disease patients' face every day of their lives by providing a forum to analyze the needs of the rare disease community and make recommendations on how to improve public policy. It is a great step toward ensuring the patients and their families have a voice in government as well as serve

as a way we can leverage the unique resources we have in Ohio that can potentially serve as an example for the nation.

Thank you Mr. Chairman and members of the committee. I will now turn it over to my colleague and once she is finished, we would be happy to answer any questions you may have.