



Testimony of

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Supporting HB 412

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Chairman Burke, Vice Chair Huffman, Ranking Member Antonio, and members of the Senate Health, Human Services and Medicaid Committee, thank you for the opportunity to submit written testimony on the benefits of House Bill 412.

Ohio House Bill 412, sponsored by Representatives Ginter and Clites, would create the Ohio Rare Disease Council. The Ohio State University Wexner Medical Center (OSUWMC) is committed to finding solutions to Ohio's, and the nation's, health challenges, including rare diseases.

In the United States, a rare disease is defined as a condition that affects fewer than 200,000 people. According to the National Institutes of Health, there could be more than 7,000 rare diseases. The total number of Americans living with a rare disease may be as high as 30 million.

H.B. 412 takes important steps in informing the General Assembly and the public on the research, diagnosis, and treatment efforts related to rare diseases in Ohio. The Rare Disease Advisory Council created by the bill will report on the coordination of statewide efforts for studying the incidence of rare diseases in Ohio; the Advisory Council's findings and recommendations regarding rare disease research and care in Ohio; and 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. In addition, H.B. 412 would require the Director of Health to publish a report detailing the incidence of rare diseases in Ohio.

One of the nation's leading academic medical centers, OSUWMC offers healthcare services in virtually every specialty and subspecialty in medicine. Thousands of patients come to us each month for treatments and services they cannot find anywhere else. Providing access to

healthcare information is central to our research, education and patient care mission. At OSUWMC, we are dedicated to improving health in Ohio and across the world through innovation in research, education and patient care.

The OSUWMC is leading the way in research for the development of treatments for rare diseases. The Ohio State University Center for Clinical and Translational Science (CCTS) provides financial, organizational and educational support to biomedical researchers, as well as opportunities for community members to participate in credible and valuable research. Funded by a multi-year Clinical and Translational Science Award from the National Institutes of Health, the CCTS leverages expertise from every college across the university, including scientists and clinicians from OSU's seven health science colleges, the College of Engineering, the Wexner Medical Center and Nationwide Children's Hospital, community health and education agencies, business partnerships and regional institutional network partnerships. The CCTS supports researchers' efforts to address rare diseases, including through hosting an educational workshop for early-stage investigators who need information about accessing and using available tools and resources to get their rare disease research project up and running.

Our focus is to advance the science of translation by turning observations into interventions. We are committed to partnering with you in your efforts to address rare diseases.

Passage of H.B. 412 will help Ohio take strides to increase knowledge about rare diseases in the state, which ultimately can lead to more diagnoses, treatments, and cures. I ask the Committee to pass this important legislation.