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**Testimony for the House Appropriations-Human Services Committee Hearing on April 9, 2019**

**RE: HB2259 EXPERT Support**

I am John Conrad, president & CEO of the Illinois Biotechnology Innovation Organization, also known as iBIO.

Thank you, to the chairwoman, and members of the committee for giving me the opportunity talk with you today about HB2259.

IBIO is the state trade association representing the 85,000 life sciences jobs in Illinois. Our membership ranges from global corporations to startup companies in the biopharma, medical device and nutrition industries coming out of our academic research centers.

New, innovative treatments provide a significant, durable benefit and value for patient health outcomes, delivery of care, and overall healthcare spending. These therapies are aimed at serious and rare diseases where patients often have limited treatment options. Examples of transformative therapies include cellular and gene therapies, which are truly personalized medicines that target treatment to specific patient populations or subsets of patient populations. These innovative drugs and Biologics have the potential to transform the treatment of rare diseases.

Approximately 30 million Americans suffer from one of nearly 7,000 rare diseases. Of those 7,000 diseases only 5% have treatments which are often complex and require supervision by specially-trained, expert physicians and practitioners. Furthermore, proper diagnosis, timely treatment and appropriate access to approved therapies is critical for individuals living with a rare disease, and ultimately is essential for cost effective treatment and management.

80% of rare diseases are genetic in origin, and approximately 50% of the people affected by rare diseases are children, of which 30% will not live to see their 5th birthday.

HB 3268/2259, EXPERRT is Expertise in Review of Rare Treatments, and what the legislation will do is ensure Medicaid access decisions with regard to medicines for rare diseases and

precision medicines are made in consultation with experts, if proposed policies are more restrictive than the FDA label and ensures timely review of these medicines. This DOES NOT remove the state's ability to implement appropriate utilization requirement. When Medicaid is making clinical coverage determinations for rare disease and precision medicines, it is vital to have the greatest set of clinical resources available which may include input from physicians, pharmacists and other medical experts who specialize in the treatment of the disease. Current Drug & Therapeutics committee members often do not hold expertise in rare disease.

This legislation serves to provide additional expertise and insight during the Medicaid review process if Medicaid proposes to limit access to medicines more restrictive than the FDA label providing for a more robust review of uncommon disease-states as novel products and therapies enter the marketplace. (Timely review is also ensured for rare disease. Current review times is no sooner than 6 months this bill would require review within 90 days. )

IBIO believes that it is imperative that the reimbursement system appropriately and adequately reflect the value of these therapies by ensuring timely, appropriate review by the Drug & Therapeutics committee.

Thank you for your time today to discuss HB 3268/2259