March 3, 2023

Dear Members of the House Health and Finance Committee,

Thank you for the opportunity to comment on SF168. The Rare Access Action Project (RAAP) opposes HF 17 as we will outline in our comments.

The legislation will not lower patient out-of-pocket costs as it does not require health plans or pharmacy benefit managers to set the price a patient pays for a prescription drug at the upper payment limit. Further, in the legislation there is no guarantee rare disease patients will pay less for their prescription medications as the bill does not address the underlying issues with plan design.

Patients would have reduced access to potential life-saving therapies in the state (e.g., if a payer cannot obtain a therapy at the state-prescribed price, and/or if a pharmacy or dispensing provider cannot stock the drug because it too cannot meet the state prescribed price, then the medicine will not be available to patients). Additionally, providers could be left with substantial costs if they acquired the drug before the price control is in place yet could not bill for the reimbursement that covers their acquisition costs once the provisions become active.

The result for patients could be catastrophic for rare disease patients who often seek care with a limited number of specialists who are also have experience with their needs.

- Patients may be required to travel, sometimes out of state, if their regular provider, hospital or clinic is unable to offer the medication they need.
- Patients may no longer be able to access their prescription at their local pharmacy,
- with the pharmacist who they have an established a long-term relationship with.
- These scenarios are particularly burdensome for patients who: rely on public transportation; are forced to take unpaid time off for their care; are the primary caregivers for children or elderly family members; or have disabilities.

In addition, we ask the committee also to take into consideration that the federal government has already enacted drug price controls (contained in the Inflation Reduction Act of 2023) that will negatively impact the development of new therapies for rare diseases. In fact, we have already begun to see the notifications of cancelled rare disease programs attributed to that legislation. At this time, it is unclear how much HF

17 would impact new drug development for rare diseases and conditions, but it can only make it worse.

RAAP is a registered 501(c)(4) non-profit organization that is a coalition of life sciences and patient stakeholders that explore creative policy solutions to address structural issues in access and coverage. Our priority is to help ensure rare disease patients have access to the care and treatments they need and submits the following comments consistent with that objective.

Thank you for the opportunity to share with you our insights into these issues. We would be willing to follow-up with you further.

Sincerely,

Michael Eging

Executive Director

Rare Access Action Project (RAAP)