January 14, 2018: Comments on the Healthcare Cabinet Recommendations for Addressing High Prescription Drug Prices

On behalf of all Connecticut residents with chronic medical conditions, the CT Rare Action Network thanks the Connecticut Healthcare Cabinet for addressing the impact that increasing prescription medication costs are having on our state budget and Connecticut families. While we agree that the escalating costs for prescription medications need to be brought under control, we feel the state needs to make sure that all recommendations for controlling these costs are not at the expense of the state residents who actually need and use these medications—PATIENTS.

We thank the Cabinet for adding consumers with patient or family experience managing medication needs for complex medical conditions to the work groups addressing this issue and hope that the emphasis on the ***patient view*** will be involved in all further discussions on this topic. We are however, concerned about the short comment period for this complex issue and we ask the Cabinet to consider extending the public comment period for a minimum of another two weeks (or until the February Cabinet meeting) since January 15 is a holiday for many state residents.

Our comments on the prescription drug draft report recommendations are as follows:

1) We support all recommendations for transparency, price justification/price-gouging, and lowering patient's out-of-pocket costs—especially the recommendation that co-insurance payments be based on the actual price negotiated by a PBM and not on the list price (current practice).

2) We support the recommendation to create a Drug Review Board (DRB) to regulate cost increases. However, since decisions made by the DRB could have a marked (possibly harmful) impact on patients and their families, it is imperative that consumers who actually use prescription medications (patients and their caregivers/family members) and the healthcare providers who prescribe these medications (physicians) must be adequately represented in the board. We recommend that the DRB **consist of 1/3 consumers who are patients (and family members) with actual experience managing prescription medication for complex, chronic health conditions.**

3) We oppose the LEGISLATIVE recommendation requiring manufacturer, PBMs, health insurers, and other payers to report payments made ***only to non-profit patient advocacy groups*** to the Office of Ethics. We do not understand why the Cabinet chose to single out patient advocacy groups in this recommendation when there are a number of healthcare, health policy, and health

economics non-profit organizations that take also money and gifts from manufacturers, insurers, PBMs, healthcare facilities and even the state—shouldn't these organizations be reported to the Office of Ethics as well? We recommend that this recommendation be changed **to and state that any individual or non-profit (including patient, healthcare, health policy, and health economics organization) participating in discussions about state policies or decisions related to prescription medication costs should be required to disclose all funding sources.**

4) We do not see the need for an ADMINISTRATIVE recommendation for SIM Quality Council to create CORE measures placing responsibility for medication adherence and communication for drug prices on physicians/medical home. Under the current system physicians deal with numerous PBMs (all having different pricing) and under the current system, physicians are not paid for this service

5) Other issues we support and would like to see the state explore are:

a. The possibility of creating a state-administered revolving loan program to help patients/families with the hardship of high-deductibles or high co-insurance payments for life-saving medications (improved medication adherence)

b. Including patients in any workgroup or committee to evaluate risk/benefits of adding exclusions or more rigorous prior authorizations to Medicaid formulary

c. Setting co-payments and co-insurance payments at maximum of $250-500/month

Closing comments:

Since consumers are currently responsible for paying more of their health care costs, groups such as AARP and NPAF feel that it is now imperative that PATIENT views on value and cost-effectiveness of treatments need to be heard. For physicians and patients cost of a medication is often secondary to clinical outcomes (improved quality of life) ease of use (complexity of the treatment--including pill splitting); patient-physician treatment decision making, safety and effectiveness of the treatment, treatment-related side effects (adverse events or complications) , AND most important to patients is the TRUE COST OF TREATMENT to the patient and their families/caregiver--will the treatment lead to travel expenses, lost work time, long-term complications, or increased (exorbitant) out-of-pocket costs.

According to reports from the Urban Foundation, AARP, the Kaiser Foundation and the National Patient Advocate Foundation (Medical Debt), approximately 1 in 4 Americans in 2017 reported having trouble paying for their medical bills...and low-income families who are enrolled in low or no-deductible plans reported spending as much as 20% of their income (after-tax) on out-of-pocket costs for healthcare--often for non-formulary meds.

According to IMSHealth (data cruncher that tracks physician prescribing) ~84-86% of the prescriptions filled in the US are for generic drugs. While most generic medications work well

for many patients, several national patient advocacy groups feel that when the Health Care Cabinet looks at reducing drug costs in Connecticut we need keep on the cost of the medication while making decisions that are flexible enough to accommodate the needs of ~15-20% of patients with complex health care needs--these are the patients that are most likely to have reactions to variations in their medications and drive up overall healthcare costs....what good is a cheap pill that a patient cannot (adverse reaction) or will not use (can't split the pill)
. Medication adherence and WASTE are two issues that the Cabinet also needs to explore.

Thank you for your time and consideration.

Lesley Bennett
Connecticut Volunteer State Ambassador

tel (203)348-1321 | **mobile** (203)829-7650
email lesley.bennett@rareaction.org