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May 31, 2024

The Honorable Susan R. Donovan, Chair  
House Health and Human Services Committee  
2 Rego Avenue  
Bristol, RI 02809

**Re: Patient Group Concerns about SB 2719**

Dear Chairwoman Donovan,

The Global Healthy Living Foundation (GHLF) is a 501(c)(3) patient advocacy group that works to improve the quality of life for people with chronic disease. GHLF represents thousands of chronically ill patients in Rhode Island and millions across the U.S. On their behalf, we oppose Senate Bill 2719 and urge you to take a pause before authorizing this review board.

By way of background, GHLF is a 25-year-old 501(c)(3) patient organization reaching millions of chronically ill patients and their caregivers across the country through social media, community events and our online support and education. GHLF works to improve the quality of life for patients living with chronic disease by making sure their voices are heard and advocating for improved access to care at the local level. Our patients have chronic conditions including arthritis, psoriasis, gastrointestinal disease, cardiovascular disease and migraine. As a result, these patients incur significant financial burden due to the high cost of the treatments that are necessary to manage their life-long disease.

As a patient-focused organization, we are constantly searching for new legislative reforms that can benefit patients and reduce their high costs. While we are encouraged by the intention behind SB 2719, which would create a drug pricing review board that aims to reduce drug costs, we have some concerns about the creation of, and intentions behind, this review board.

The focus of these reforms is in the wrong place. This board would be given the authority to set reimbursement caps. However, these caps will do little to lower the costs that patients pay at the pharmacy counter because patient costs are not based on reimbursement; they are based on the list price of a drug. By choosing to focus on the reimbursement part of the equation and not a way to detach patient costs from the artificially inflated list price, this board could have the adverse impact of reducing access and affordability for patients. A downstream effect of setting these caps could also be that smaller, local pharmacies will no longer be able to stock medication that has a list price higher than the reimbursement caps. Pharmacies in the state will face the choice of either stocking those medications at a loss or they will choose not to stock them at all, forcing patients to use national specialty pharmacies and reducing their access further.

Additionally, while we are encouraged by the mandated inclusion of at least two patients on the board, we are concerned that these patients, and other patient voices at large, will be ignored as the state tries to acquiesce to outside pressures to do something related to drug spending, as we have seen in other states. We want to ensure that patient voices and concerns are given proper consideration and taken seriously throughout this process. We hope to see a focus on how to reduce patient out-of-pocket spending at the pharmacy counter through reforms of the complex reimbursement methods employed by insurers and pharmacy benefit managers (PBMs).

We hope that during further discussions about this bill in committee the discourse focuses more on how to the ultimate price the patient pays for the medication and not how much a payer can reimburse for it. Thank you for your work to improve the lives and health of Rhode Island residents.

Sincerely,

A handwritten signature in black ink, appearing to read 'Corey Greenblatt', written in a cursive style.

Corey Greenblatt, MPH  
Director of State Policy and Advocacy

