

Good afternoon, Chairperson and Distinguished Members of the Rhode Island Senate Health and Human Services Committee.

My name is Justin Kim, and I live in Providence, Rhode Island. I am a third-year medical student at the Warren Alpert Medical School of Brown University. I serve as Co-President of the inaugural NORD Students for Rare chapter at Brown University, where I helped write the Rare Disease Advisory Council bill that was passed in Rhode Island. I also serve as a reviewer for the National Organization for Rare Disorders State Report Card and am someone with family members living with rare diseases. I am here today to respectfully ask for your support for Senate Bill No. 2468, the Benefit Determination and Utilization Review Act.

This legislation is critical to protecting patients from unnecessary barriers to treatment. The Benefit Determination and Utilization Review Act would protect rare disease patients by prohibiting step therapy from being applied to medications prescribed for the treatment of rare diseases. It would also safeguard access to care by requiring insurers to ground their step therapy protocols in medical guidance, provide exceptions that consider patients' medical backgrounds through transparent processes, and respond to exception requests within defined and expedited timelines.

Rare disease patients who spend years on diagnostic journeys should not be barred from accessing effective care prescribed by their health care provider. These protections would reduce barriers to treatment for individuals who often go years before receiving a diagnosis, let alone an effective therapy. For many families, timely access to the right medication can mean the difference between hope and uncertainty.

My commitment to this issue is both professional and deeply personal. As a future physician, I am trained to deliver evidence based and compassionate care that places patients at the center of every decision. However, step therapy policies can delay or deny treatments deemed medically necessary by clinicians, forcing patients to endure ineffective therapies before receiving the care they truly need.

As someone with family members affected by rare diseases, I have witnessed the emotional toll these barriers impose. The uncertainty, the waiting, and the fear of losing precious time are realities that no patient or family should have to face. This legislation ensures that medical

decisions remain guided by clinical expertise and patient need rather than administrative obstacles.

The need for this reform in Rhode Island is clear. According to the National Organization for Rare Disorders State Report Card, Rhode Island currently receives a grade of F in the area of step therapy. Passage of this bill would elevate the state's score from an F to an A, demonstrating Rhode Island's commitment to protecting vulnerable patients and advancing equitable access to care.

This bill is about more than policy. It is about people. It is about ensuring that Rhode Islanders with rare diseases receive timely, effective treatment and the dignity they deserve.

I respectfully ask the Rhode Island Senate Health and Human Services Committee to support Senate Bill No. 2468 to improve access to care and quality of life for Rhode Islanders impacted by rare diseases.

Thank you for your time, your service, and your dedication to the health of our communities.

With gratitude,

A handwritten signature in black ink, appearing to read "Justin M. Kim". The signature is fluid and cursive, with a large initial "J" and "K".

Justin M. Kim