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for Rare Disorders

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February 5, 2021

The Honorable Matthew J. Shepherd
Speaker of the House
Arkansas House of Representatives
State Capitol Building
500 Woodlane Street, Suite 320
Little Rock, Arkansas 72201

Dear Speaker Shepherd,

On behalf of the 1-in-10 individuals living in Arkansas with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for scheduling floor consideration for Senate Bill 99 (SB 99). SB 99 would provide a much-needed update to the state's step therapy law and implement common sense patient protections. NORD was pleased to see the Arkansas State Senate and the House Public Health, Welfare and Labor Committee pass SB 99 unanimously. We urge you to support this important legislation and swiftly pass it out of the House of Representatives.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD believes strongly that all patients deserve the medical care that is best suited for their medical situation and will give them the best results. Based on the reports we receive from individuals affected by rare diseases; step therapy is increasingly being applied by health plans in Arkansas with little regard for a patient's treatment history and specific medical needs.

Step therapy, also known as "fail first," is an insurance company practice that requires patients to try and fail one or several medications chosen by their insurer before allowing them to take the medicine prescribed by their provider. Step therapy protocols vary widely among insurers. Navigating an appeal can be confusing and time consuming for patients and their health care providers, sometimes taking weeks or even months. This process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations.

Although Arkansas has some safeguards in place, we ask your support of SB 99 to allow patients better access to the most appropriate treatments prescribed by their health care providers. This would be accomplished by:

- Ensuring step therapy protocols are based on widely-accepted medical and clinical guidelines;
- Creating a clear and expeditious appeals process – requiring a reply within 24 hours for an emergency or 72 hours for a non-emergency;
- Protecting patients who have already tried and failed a drug or for whom a drug is expected to be ineffective;

- Protecting patients whose conditions are well-controlled on a prescription from being required to try a new medication against their provider’s recommendation or for whom the medication is contraindicated or likely to cause harm; and
- Protecting patients when their provider recommends a specific medication due to medical necessity.

It is important to note that SB 99 does not ban the use of step therapy. However, in order to guarantee patient safety, Arkansas needs to ensure that step therapy policies do not interfere with appropriate care for rare disease patients and families. By voting in support of SB 99, you will be protecting patients while still enabling health plans to achieve the cost saving benefits of step therapy when appropriate. Given the additional challenges of the COVID-19 pandemic, now is a logical time to update the state’s step therapy law to avoid some of the unnecessary burdens on patients, providers and the health care system that could be prevented with appropriate and timely care.

Once again, on behalf of the Arkansas rare disease community, we thank you for putting SB 99 on the House of Representative’s agenda for floor consideration and urge its swift passage. For any questions, please feel free to contact Alyss Patel at APatel@rarediseases.org. Thank you for your consideration.

Sincerely,

Alyss Patel

Alyss Patel
State Policy Manager, Western Region
National Organization for Rare Disorders

Tammy Jones

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