

Policy Focus Areas

Healthcare policy reform must account for the unique challenges of rare disease drug development and reject one-size-fits-all approaches that risk unintentionally harming the ability to make treatments available for rare, medically underserved patient populations. With more than 90% of rare diseases without a viable treatment, rare disease companies are dedicated to responding to the urgent needs of people with rare diseases.



Ensure Accessibility and Protect Innovation

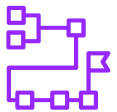
Advance ethical and sustainable solutions to ensure that all rare disease patients who can benefit from the life-changing innovations have timely access to them.

Protect against blunt drug pricing control policies that threaten rare disease innovation and patient access.



Enable Earlier Diagnosis

Support equitable and early access to lifesaving genetic testing and diagnostics, including the continued success and modernization of our nation's newborn screening system, to enable earlier treatment and better health outcomes.



Support a Robust Development Pipeline

Preserve and support optimized research incentives to continue to attract and maintain long-term investment in the development of advanced treatments and diagnostics for rare diseases.

We are dedicated to being a reliable and trusted resource for our leaders in Congress and the Administration, and a productive partner to rare disease-minded industry, academic and patient groups, by educating on the issues and opportunities that affect rare disease companies and advancing our shared mission to improve the lives of people living with rare diseases.

For more information, please visit www.rarecoalition.com or contact info@rarecoalition.com.
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