RAAP

RARE ACCESS ACTION PROJECT

Rare or orphan diseases are classified as any disease that affects less than 200,000 Americans.

THE RARE ACCESS ACTION PROJECT (RAAP)

RAAP is a non-profit (501 c4) organization whose membership consists of patient advocates, emerging life science companies, and other rare disease stakeholders advocating for innovative solutions to reduce or eliminate barriers to rare therapies.

THE SITUATION

Many rare disease patients, upon a diagnosis, believe that because they have coverage (commercial, Medicaid or Medicare) that they will be able to utilize the medicine or therapy that was developed for their disease. The fact is:

- **Patients.** Patients and their families (50 percent of people with rare diseases are children) often struggle for 6-12 months and in many cases for years fighting for payer coverage and access to innovative rare technologies. In other cases, patients and families struggle to afford the co-payments associated with rare therapies.
- **Providers.** Health care professionals struggle to provide the best care available for rare disease patients whose insurance does not cover the therapy and the patient is unable to cover the out of-pocket-costs.
- **Payers.** Private and public payers (such as Medicare and Medicaid) struggle to plan and pay for rare patients, particularly when a product might be used by only a few thousand, a couple of hundred or even a mere dozen individuals.

CURRENT RAAP INITIATIVES

- **Protect Research and Development for Rare Disease—**ensure health policies do not undermine the investment in innovation for rare diseases;
- **Ensure Rare Disease Representation in Coverage and Access—**require government programs to impanel rare specialists and patient/patient advocates to ensure that the rare perspective is included in decision-making at the federal, state, and local level;
- **Address Rare Disease Patient Cost Share Burden—**implement cost share policies that address the disproportionate effect on patients with rare diseases. For example, capping out of pocket costs for rare patients in the Medicare Part D program or ensuring all patient copays are counted toward out-of-pocket costs by commercial plans;
- **Propose Innovative Solutions to Manage the High Cost—**propose payment solutions such as reinsurance or value-based pricing to ensure access to rare therapies at FDA approval; and
- **Protect and Improve Timely Access to Innovative Treatment—**implement policies that permit access to rare therapies at FDA approval across payers, including therapies with FDA Break Through and Accelerated Approval that meets significant unmet medical needs.

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