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TOPIC: Press Releases, Featured News, Most Favored Nation Policy

**For Immediate Release**

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**Haystack Project Opposes Administration’s “Most Favored Nation Policy” for Medicare Drug Costs**

*The Most Favored Nation Executive Order intended to lower drug prices in the Medicare program by tying them to the lower prices paid in other countries Raises Significant Concerns for Rare and Ultra-Rare Patients*

**Annapolis, MD, September 25, 2020** – Haystack Project and the Rare Cancer *Policy* Coalition has significant concerns about the impact of any one-size-fits-all initiative to cut Medicare expenditures for patients with rare and ultra-rare disease and rare cancers. Targeting Medicare drug reimbursement poses a significant threat to the viability and sufficiency of incentives that patients rely on to encourage innovator investment in treatments for very small populations.

Congress carefully considered the balance between patient access and Medicare program expenditures in crafting the average sales price (ASP) statutory reimbursement structure for Part B drugs. And the Part D program presents a myriad of hurdles to patients requiring prescription drugs to manage rare disease symptoms and/or reduce disease progression. Adding another layer of complexity with a drug pricing mechanism based on international drug prices could be particularly problematic for drugs treating rarer conditions that have lower sales volume upon which to establish an international reference price.

Patients suffering from the rare and ultra-rare conditions represented in Haystack Project and RCPC’s work suffer the “unintended consequences” of policies like these all too often, especially when the primary or sole focus of that policy is to reduce Medicare costs. Our patients and their clinicians continually struggle with payment systems and mechanisms designed to address more common conditions. Overcoming access obstacles requires focus, persistence, and a significant time commitment by our patients, their families and caregivers. Anything that reduces provider payments or otherwise erects new obstacles to care can represent the tipping point on access so critical to our patients.

Haystack Project is also concerned that the Administration will be implementing this policy initiative through a model test. **Medicare's model authority only allows the Administration to test innovations that *improve or maintain patient outcomes*.** We are unaware of any evidence that can confirm that patients *will not have decreased access* to the treatments they need, leading to poorer outcomes if Medicare implements this Most Favored Nation policy for drugs. Medicare's elderly and disabled population is disproportionately comprised of individuals with multiple chronic conditions and complex interactions between these conditions and their treatments. It would be difficult to imagine a population less suited to studying impacts of a drug pricing model that completely diverges from the existing US distribution and pricing realities. Using the Administration's model testing authority without robust and clear evidence confirming that patient care, treatment options, and outcomes would not be adversely impacted for ANY patients, appears to cross the line between refining policy and actively experimenting on a vulnerable patient population.

### **About HAYSTACK PROJECT**

**Haystack Project** is a 501(c)(3) non-profit organization enabling rare and ultra-rare disease patient advocacy organizations to coordinate and focus efforts that highlight and address systemic reimbursement obstacles to patient access. Our core mission is to evolve health care payment and delivery systems with an eye toward spurring innovation and quality in care toward effective, accessible treatment options for rare and ultra-rare patients. We strive to amplify the patient and caregiver voice in these disease states where unmet need is high and treatment delays and inadequacies can be catastrophic.

**The Rare Cancer *Policy Coalition (RCPC)*** is a Haystack Project initiative that brings together rare cancer patient organizations. RCPC gives participants a platform for focusing specifically on systemic reimbursement barriers and emerging landscape changes that impact new product development and treatment access for rare cancer patients. It is the only rare cancer coalition developed to focus on and respond to reimbursement, access and value issues across the rare cancer community. Working within the Haystack Project enables RCPC participants to leverage synergies and common goals with rare and ultra-rare patient advocates and optimize advocacy in disease states where unmet need is high and treatment inadequacies can be catastrophic.