Access to Rare Indications Toolkit

Bill Basics

This bill levels the playing field for rare disease patients trying to access medically necessary care by requiring insurance companies to use additional sources to determine when treatments are medically necessary.

There are often so few patients with a very rare condition that drug companies will not, or often cannot, do a clinical trial for every subtype of a rare condition. Insurance companies often refuse to cover medically necessary treatments to rare disease patients. Patients are then left fighting for access to a treatment. And – patients only get sicker and their care more expensive while they wait for the care their doctors say they need.

The Access to Rare Indications Act will help put rare disease patients on equal footing with other patients, so they have the same chance to get treatment.

Resources

- Letter to Senate re: Original Cosponsorship
- One Pager
- STATnews article

Social Media Kit

Below are some sample Facebook, Linkedin and Twitter social media posts. Images are below.

The hashtag for this effort is #raredeservescare

- **To ask your member of Congress to co-sponsor:**
.@[insert legislators] Please co-sponsor the Access to Rare Indications Act. Patients with #rarediseases need EQUAL access to life-altering medicines too. #raredeservescare @haystackproject

- **Announcing your organization's support for the bill**
We support the Access to Rare Indications Act because people with #rarediseases need the same swift access to medically necessary treatments as everyone else. #raredeservescare @haystackproject


HAYSTACK PROJECT
The Voices of Rare & Ultra Rare
Support the Access to Rare Indications Act
#raredeservescare


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#raredeservescare