

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare

APRIL RECAP

APRIL 2024

HAVE YOU HEARD THE NEWS?



Dr. Janet Woodcock Joins Haystack as Mission-Focused Advisor
See *Pink Sheet* coverage [here](#).



ACCOMPLISHMENTS

April CMS Meeting -- Haystack's April meeting with CMS on the IRA drug price negotiation program centered on CMS' interpretation of QSSD. We discussed two drugs on the current negotiations list to highlight how combining divergent indications with potentially variable dosing ends up going against the statutory theme of a "single price" for negotiation purposes. We talked about repurposing and its importance for rare and ultra-rare patients.

- The April and May meetings follow on the heels of CMS meetings where Haystack patient groups joined us to discuss IRA Listening Sessions and CMMI VBA Models. Haystack continues to invite your group to let us know if you are interested in participating in CMS meetings with us.

MORE WITH CMS

May CMS Meeting -- Haystack will be meeting with CMS' Inpatient (IPPS) team in May. Please **reach out to us** if your patients are *admitted to the hospital* for their care or get your treatments in the inpatient setting. **We are collecting information and stories on patients' inability to get appropriate access to clinicians, treatments, etc. for our CMS discussions.** We of course have a long-standing position on the inadequacy of the DRG framework for low-volume/high-cost treatment options. Haystack patient organizations discussed the need for regular input to CMS to highlight why policies that may work well for patients with more common conditions can be problematic for rare diseases.

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H.R. 6094 PROTECT RARE ACT



Discussion continued on how to break the log jam with Chairman Wyden's office, requiring a pause on the Senate introduction. Patient groups discussed the need for physicians and patient engagement in Oregon. If you have patients, caregivers, doctors, etc. in Oregon (even if they go to Seattle or nearby cities for their care), **please let us know**. Please tune into our monthly workgroup calls, where we discuss tactics in depth. [Ask us](#) for the calendar invites – everyone can join!

SURVEY - 5 QUESTIONS



Please fill out [this survey](#) to help Haystack help your patient community.

Just 5 questions in 7 minutes (!) tells us enough to know if the policy work we are doing will help remove the right insurance barriers for your patients.

IRA WORK CONTINUES

Haystack submitted its second comment letter to CMS on the “smoothing” program that will allow patients who enroll to spread their prescription drug costs over a plan year. We expect this new program kicking off next year to help a majority of rare disease patients, so we want to make sure CMS rolls it out so it's understandable and easy for patients. ***This letter*** shared rare patients' feedback on CMS' six “model” documents - highlighting changes CMS should consider to make documents clearer for patients. You can read our letter [here](#).

SPEAKER SERIES

Please check out our most recent webinar with BMS' Senior Vice President, Ranjani Durham talking about value-based arrangements and rare diseases [here](#).



RARE IN THE STATES

Haystack discussed Prescription Drug Affordability Boards (PDABs) and the recent efforts to carve out rare in Colorado.



MEDICAID AND RARE

Groups discussed the recent Kaiser Family Foundation report on how 'unwinding' is progressing. Given the incidence of rare diseases in children, we discussed how slow the state's progress has been in re-enrolling patients and the resources available to aid our groups in supporting their communities.

HOUSEKEEPING

DUES, DUES, DUES! Pay your 2024 dues [here](#). Please help us keep up all the good work you've come to count on us for!

Do you have calendar invitations for our standing monthly calls?

3rd Wednesdays 1-2 pm ET - Member calls with patient groups

Follow us on social media – [LinkedIn](#), [Facebook](#), and [Twitter](#).
Any questions, contact Tiara.Logan@haystackproject.org



THANK YOU TO THE SPONSORS

Please check the website for the growing list of Haystack sponsors, whose support allows us to do what we do!



Haystack Project is grateful to all of our Alliance Partners for lending their insights and perspectives, as well as for combining their efforts with ours to better serve the rare and ultra-rare communities.