

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare

FEBRUARY NEWSLETTER

FEBRUARY 2022

Housekeeping

100% Participation: Please take 5 minutes today to...

- 1) Pay your annual dues [here](#)
- 2) Follow us on Social Media! Click on the images provided.



Rare Disease Week 2022

Haystack Project is hosting a Rare Disease Week Panel Discussion

Tuesday, Feb 22, 2022 from 3-4pm ET/12-1pm PT

Come join us to learn more about leveling the playing field for rare disease patients seeking medically necessary care.

Speakers:

Christina McCauley: healthcare policy, Congresswoman Matsui
Marc Yale: past research & advocacy lead, IPPF
Dr. Robert Carlson: CEO, NCCN
Dr. Darcy Krueger: University of Cincinnati College of Medicine
Dr. Emanuel Mavarkis: University of California Davis

[Register Here](#)

RARE
DISEASE WEEK
ON CAPITOL HILL

If you talk about HR 1184 and HR 6160 at your meetings, let us know which offices were interested.

We are happy to follow up!

- HEART Act (HR 1184) - improves FDA engagement with patients during an application's review process.
- Access to Rare Indication (HR 6160) - levels the playing field for rare disease patients seeking medically necessary care.

Rep. Matsui (D-CA) just released a "Dear Colleague" letter asking for co-sponsors for HR 6160.

[Share her letter on the Hill.](#)

[Read & Share](#)



LEGISLATION

Haystack has gotten two bills introduced in Congress to (i) improve FDA engagement with patients during an application's review process (H.R. 1184) and (ii) level the playing field for rare disease patients seeking medically necessary care (H.R. 6160).

We discussed the different "trains" that bills can attach themselves to in an effort to get enacted into law. And, we talked about how this process works.

Please use [VoterVoice](#) to ask your Senators and Representatives to support both! And post VoterVoice on your own websites and social media to help increase the noise!!

Ask me [here](#) to show you how!
We paid \$10k for this tool so you don't have to!
Please use it!

[Visit Voter Voice](#)

REGULATORY

We talked about CMS's National Coverage Analysis on Aduhelm, and Haystack Project's comments to CMS on the use of accelerated approvals to deny access.

We discussed CMS' recent/expected activity on the concept of Direct Contracting Model in Medicare and the implications for rare diseases. In this context, we reiterated our earlier concerns about ICD-10 coding for rare diseases.

CMS released a Request for Information during our monthly call related to Medicaid and CHIP. Comments are due in 60 days. If you would like to share your community's Medicaid/CHIP experiences with us, check out the topics here. Haystack Project will respond to CMS' RFI.

[Read More](#)

WORK GROUPS

We discussed the need for workgroups for deeper dives on certain issues. Email us here to join one or more of the workgroups below (or suggest a new one).

1. Heart Act Work Group – patient group engagement with FDA during a pending application

2. Access to Rare Indications Work Group – Join us If your patient community uses any treatments off label and have a hard time getting them paid for by insurance.

3. Diagnosis by Observation/"First Look" – We are working on identifying rare diseases that can initially be detected initially by observation. Do you know of one? Do you have a doctor on your board or advisory that could help?

4. State Capacity Building – We are identifying a set of pilot states and rare conditions where state Medicaid programs may seek to limit patient access. Come join us to pilot a training program for patients and caregivers.

5. Diagnostics – We are learning more about whole genome sequencing, multi-cancer early detection, and other efforts to shorten the diagnostic journey. Join this working group for a deeper dive and focused advocacy.

[Email us](#)



WE ARE LOOKING FOR AN INTERN

Researches legislation, drafts memos, talking points, advocacy materials, compiles data provides, provides event and meeting support, and tracks and reports on advocacy and lobbying efforts

Knowledge of environmental advocacy and/or national politics preferred

[Email us](#)

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!



The 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.

