

# HAYSTACK PROJECT

## The Voices of Rare & Ultra Rare

DECEMBER RECAP / NEWSLETTER

DEC 2022

## WE DID IT!

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Haystack Project couldn't be prouder of the work our patient groups did to get the Heart Act over the finish line! Haystack helped them conceive the provisions, then draft, negotiate, edit, research, and meet (over and over!) with key offices. The shared effort came together Dec. 29 when the President signed the Omnibus package! [Congrats to all the patient groups who worked so hard and never gave up on making a difference!](#)



## YEAR IN REVIEW

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Our [Annual Review](#) is hot off the press! This represents an “[annual report](#)” of sorts for Haystack Project. We document all our work for the year [right here!](#) Please take a look and reach out to us with questions and ideas, but also see if it suggests any new ways you'd like to work with Haystack!

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# HOUSEKEEPING

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Get a head start and pay your 2023 dues [here](#).

**Dues paid early mean you won't receive email reminders for the rest of the year!**

## WE'RE MOVING

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Our standing Thursday calls will **NO LONGER BE ON THURSDAY AFTERNOONS**. We heard you and responded!

Update your calendars TODAY!

- **Third Tuesdays 1-2 pm ET -- Speaker Series calls**
- **Third Wednesdays 1-2 pm ET – Member calls with patient groups**

Thank you to those who filled out the survey on your availability. Both calls will begin in February 2023 (no Jan. call).



# LEGISLATIVE

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Work continues on Haystack Project's other bill, HR 6160. Join us in making this a success too! Our Senate Fly-In was very productive, and we want to keep the momentum in January!

We are also actively identifying/analyzing other patient access issues that might lend themselves to a legislative fix. We are talking to all our members and partners and, of course, reviewing the priorities everyone gave us the last time we did this. We welcome new ideas too.



# REGULATORY

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Government agencies critical to Haystack's mission got a lot off their desks just before the holidays! As a result, we will be spending time analyzing proposals for how they impact the rare and ultra-rare communities. The following boxes are just a heads-up on proposals and upcoming deadlines. Our work never stops. We have lots to discuss in January!

# REGULATORY CONTINUED

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## AHRQ SEEKING EVIDENCE TO ADDRESS HEALTH DISPARITIES.

The Agency for Healthcare Research and Quality (AHRQ) is seeking scientific information submissions to inform its review of healthcare system-level strategies to address racial and ethnic disparities in health and healthcare. The submission deadline is January 11.

## SENATE LETTER ON DUAL ELIGIBLES.

A group of six bipartisan senators requested information on care coordination and integrating care for dual eligibles (patients that qualify for both Medicare and Medicaid). Comments are due on January 13.

## MEDCAC MEETING.

The Medicare Evidence Development and Coverage Advisory Committee will meet on February 13 and 14 to consider requirements for studies on treatments CMS will cover. These studies would take place after studies done for FDA and after FDA approval. Further trials for CMS would mean randomizing patients into trials for treatments already approved for use, raising several access barriers and legal issues. Comments are due January 13. Haystack has commented on this topic and will continue to point out how concerning this is for rare patients.

# REGULATORY CONTINUED

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## CMS RFI ON ACA'S ESSENTIAL HEALTH BENEFITS PACKAGE.

ACA/Obamacare plans are required to provide so-called "Essential Health Benefits," and CMS wants input on, among other things, emergency health benefits, how employer benefits have changed since 2014, and their impact on EHBs.

Responses are due by January 31.

## NBPP.

CMS released its annual policy changes for ACA plans. Comments are due 45 days after official publication in the Federal Register.

## PRIOR AUTHORIZATION PROPOSED RULE.

CMS proposed policies to advance interoperability in prior authorizations to improve electronic processing, reduce physician burden, and improve patient access. The comment period is 90 days.

## PART D/MA PLANS.

CMS also released its annual proposals for Part D and Medicare Advantage plans. Comments are due February 13.





As 2022 winds down, so does my time as CEO of Haystack Project. I've learned so much from the patients, clinicians, caregivers, and even our own Haystack team about the rare community. While I came to the role knowing quite a bit about rare from my time in industry, Haystack Project was a crash course in connectedness to patients as well as association management.

In my time here, Haystack kicked off several “deep dive” policy Work Groups, focused on patient community dialogue and collaboration with industry and medical societies. That may sound like a small thing, but since its inception, Haystack’s hallmark has been regular, direct, confidential educational policy dialogue with patients. It is part of their DNA. When I was still in industry, I supported Haystack because I saw first hand how they helped their patient organizations understand -- but also articulate and engage policymakers -- on issues important to all of us. In my time at Haystack, I've heard over and over from industry how much they appreciate a place to recommend to patient groups for balanced, deep dive understanding and support to exercise their “policy muscle” with lawmakers and key stakeholders.

We all know how complex healthcare can be, and Haystack Project never lets go of a patient group’s hands as they help them translate their experiences into needed policy change in meetings with Med PAC, Congress, CMS, FDA, state Medicaid, and more. The groups can participate with confidence, knowing we are by their side.

During 2022, the groups also progressed our work on H.R. 6160, and of course, successfully passed the HEART Act! Wins like the Heart Act don't come along every day, and certainly not from the smallest and newest umbrella organization representing rare diseases. You don't need me to tell you it speaks volumes for what they can achieve next with your involvement and support. If you're still on the fence, what are you waiting for? Find the resources and time to support and participate with Haystack!

As for me, my personal and professional goals for 2023 will not leave me the time Haystack needs. While the organization's policy and education efforts remain in good hands, Haystack needs a strong steward for the growth the organization has experienced in the last two years.

While I hope to be back someday, I want to introduce you to Chevese Turner. Chevese is already a part of Haystack, serving on its Board. She's not only very familiar with the organization and its mission, she brings strong experience in founding and leading a nonprofit dedicated to patients. The Board has asked Chevese to serve as Acting CEO while we search for new leadership.



Please join me and our Board in congratulating Haystack Project on its achievements in 2022, and in welcoming Chevese as she takes Haystack to the next level!

**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!



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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.

All Copays Count Coalition



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BRAIN  
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