

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare

JANUARY RECAP / NEWSLETTER

JAN 2023

SPEAKER SERIES



On February 21, 2023, at 1 pm ET, Courtney Johnson will discuss what we can expect from Congress this year. 2023 kicks off a two-year Congressional session with a very closely divided Congress!

The 2023 Speaker Series kicks off Tuesday, February 21, at 1 PM EST. [REGISTER HERE](#) to join this session.

Who would you like to see Haystack host next month on our Speaker Series? Send your suggestions [HERE!](#)



LEGISLATIVE & REGULATORY

Haystack CED Study Criteria

- Several groups signed onto Haystack's response to CMS efforts to further "study" treatments already approved by FDA, thereby holding up paying for them (The policy is called "Coverage with Evidence Development," which is quite a euphemism because it stops coverage in its tracks!). Final letter here.

Senate RFI on Dual Eligibles

- Haystack responded with implications for rare disease patients to a request from six Senators asking about care coordination and integrating care for patients who are eligible for both Medicare and Medicaid ("Dual Eligibles")

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LEGISLATIVE & REGULATORY CONTINUED



Haystack NBPP

1. Several groups signed onto Haystack Project's response to CMS' annual proposal to refine how ACA plans work. We shared our disappointment/concern that CMS had not addressed areas of particular concern to individuals with very rare diseases. Patients with rare diseases and chronic conditions remain vulnerable to "discriminatory" plan designs with utilization management strategies and formulary design.



EHB RFI

1. Haystack also wrote to CMS on its RFI seeking real world information on ways in which ACA/Obamacare plans should be evolving. We focused our letter on the disproportionate challenges, including high out-of-pocket costs, rare disease patients face in receiving the care they need when they need it, the need for education and outreach to primary care providers to improve the real- world health care experience for rare disease patients, and the significant, disproportionate barriers rare disease patients face for the services needed to diagnose, treat, and manage their condition(s).

WE ARE MOVING

Our standing Thursday calls will **NO LONGER BE ON THURSDAY AFTERNOONS.**

We heard you and responded!

NEW this year – we've sent out calendar invites. You should have pre-populated invites on your calendar for the year.

3rd Tuesdays 1-2 pm ET -- Speaker Series calls
3rd Wednesdays 1-2 pm ET – Member calls
with patient groups

Both calls will begin in February 2023!



HOUSEKEEPING

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!

OTAT Town Hall Series: Clinical Development of Gene Therapy Products for
Rare Diseases [FREE REGISTRATION HERE](#)

Follow us on social media – [Linkedin](#), [Facebook](#) and [Twitter](#).

WELCOME OUR NEW CEO



Chevese Turner will serve as Acting CEO while Haystack undertakes a search for a more permanent candidate. She is steeped in Haystack's mission given her role on the Board, and she brings over 20 years in non-profit leadership to the role. The board is confident in **Chevese's** dedication to listening closely to the patient community Haystack represents.

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.

All Copays Count Coalition

