

# HAYSTACK PROJECT

## The Voices of Rare & Ultra Rare

NOVEMBER RECAP

NOV 2023

**DUES, DUES, DUES!** Pay your 2023 dues [here](#). Please help us keep up all the good work you've come to count on us for!

1:1 Listening Sessions are ongoing. Please [email](#) Tiara with any 15-30 minutes of availability, you have between now and the end of January.



## PROTECT RARE ACT

### PROTECT Rare Act or H.R. 6094

Haystack Project groups discussed grassroots work, which they are kicking into high gear. We will do a virtual fly-in again in January to add cosponsors on the House side.

Find EVERYTHING you need to learn more and advocate for this bill is [HERE!](#)

**SENATE UPDATE:** Sens. Tillis and Cassidy continue to wait on Chairman Wyden's input that will allow a Finance Democrat to join them in a companion introduction in the Senate.



**PROTECT RARE ACT**

Providing Realistic Opportunity To Equal and Comparable Treatment for Rare



NOVEMBER RECAP

NOV 2023

## HEART ACT IMPLEMENTATION UPDATE

It's been a busy month on this topic!

**National Academies** invited Haystack Project to present on Day 2 of their first meeting on rare diseases. [Click here](#) to see Haystack's presentation. [Click here](#) for PoliticoPro coverage of the meeting (page 3 covers patient groups).

**GAO Meeting** staff met with Haystack patient groups for two hours on Nov. 20th. Thank you to CDG Care, Galactosemia Foundation, MLD Foundation, IPPF, CDKL5, CLL Society, and FCS Foundation. The team did a great job! [Let Tiara know](#) if you'd like to get involved in future discussions.

**Duke-Margolis/FDA Meeting** has been scheduled for Dec. 14. [Here](#) is the link to attend. Haystack has had two pre-meeting sessions with Duke Margolis to help ensure this is a useful meeting for our community. Special thanks to the Galactosemia Foundation, CDG Care, CLF Foundation, and IPPF for meeting with Duke Margolis right after Thanksgiving too. Ironically, they lobbied hard to get Haystack a seat at this table, which wouldn't even be happening if it weren't for Haystack!?!

## COMPENDIA

### Rare Disease Compendia

Haystack Project discussed interest in compendia for rare diseases. Our groups are recruiting interested clinicians for a Q1 meeting/panel discussion!! Please [let Tiara know](#) if you're interested in the topic or in participating.



## STATE FOCUSED HAYSTACK WORK

Groups discussed input from industry, state experts, and patient groups on Haystack engagement in state advocacy, including where we can succeed, where and how to best support our members, our members' limited bandwidth, and more



## MISCELLANEOUS UPDATES



National Health Council did an interesting report on the burden of prior authorization on patients with chronic diseases.

<https://nationalhealthcouncil.org/research-briefs/nhc-report-exploring-the-burden-of-prior-authorization-on-patients-with-chronic-disease/>

## WORK GROUPS

Updates were provided on the several work groups underway, including:

**PROTECT Rare/Access to Rare Indications** – This workgroup announced the upcoming introduction of the newly named PROTECT Rare Act in the House.

**First Look Project** – This workgroup is focused on phenotypes/"tell-tale signs" of rare diseases.

**HP50** – This workgroup has a pilot underway to improve advocacy at state Medicaid departments – three states and two patient groups with recent/near approvals.

**Do you have these on your calendar?**

Please email Tiara Logan at [tiara.logan@haystackproject.org](mailto:tiara.logan@haystackproject.org).



**DUES, DUES, DUES!** Pay your 2023 dues [here](#). Please help us keep up all the good work you've come to count on us for!

## HOUSEKEEPING

**DUES, DUES, DUES!** Pay your 2023 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 Tuesdays 1-2 pm ET** - Speaker Series – Invite includes required registration link.

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

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

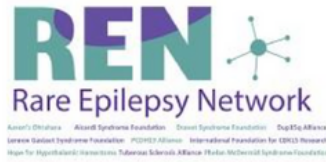
Any questions, contact [Tiara.Logan@haystackproject.org](mailto:Tiara.Logan@haystackproject.org)

### 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!*



All Copays Count Coalition



*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.*