

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare

MAY NEWSLETTER

MAY 2022

HOUSEKEEPING

1. Please pay 2022 dues today!

Thank you to the **100** patient groups that have already paid.
Help us reach our 100% participation goal!

[Pay dues](#)

2. Did your patients see a doctor/rare disease expert across state lines w/o the usual hassles during Covid? Via telehealth? Did they pay more for at-home infusions during Covid? Ask your patients to take this survey! Congress needs to appreciate the good and the bad of the Rare Covid/Telehealth Experience!

[Take Survey.](#)

ADMINISTRATIVE ASSISTANT NEEDED!

For a complete list of current responsibilities, please visit the job posting below.

Please submit resumes to
Haystack1@HaystackProejct.org

[View posting](#)



MAY NEWSLETTER

MAY 2022

LEGISLATIVE UPDATE

The HEART Act - included in the House E&C-passed FDA user fee package, now headed to the House floor.

The initial Senate package did not include the HEART Act. Another draft coming shortly, and we hope to be included.

We discussed Call to Action, asking everyone to call your Senators to request they co-sponsor S. 4071. **SEE BELOW!**

REGULATORY UPDATE

We reminded/discussed the inpatient Rare RFI and noted a draft will be ready soon. Welcome early thoughts from all!

FOR THOSE PARTICIPATING IN RARE ACROSS AMERICA

Patient groups led a discussion about how to schedule meetings during Rare Across America, and to use the materials from the Haystack website. Please email us with questions. We will connect you with the patient groups who have participated before.

Please use Haystack Project's one-pagers [HERE](#)

HR 6160 and Accelerated Approval [HERE](#)

CALL TO ACTION

CALL YOUR SENATORS TODAY!

Three easy steps...

- 1. DIAL 202 - 225 -3121**
- 2. TELL THE OPERATOR TO CONNECT YOU TO YOUR SENATOR'S OFFICE**
- 3. TELL THE SENATOR'S RECEPTIONIST THAT RARE PATIENTS NEED SUPPORT & YOU WANT THEM TO CO- SPONSOR THE HEARTACT – S. 4071!**

CALL NOW!

THEN CALL AGAIN AND ASK TO BE CONNECTED TO YOUR OTHER SENATOR

(each state has two)!

202 - 225 - 3121

ASK YOUR FRIENDS, FAMILIES, CAREGIVERS, & TEACHERS TO CALL TOO!

**Questions? Email us
haystack@haystackproject.org**

HEART & Accelerated Approval

(led by Kara Berasi, CDG Cares)

Kara reported the group's first call led to a Call to Action.

Meets second Mondays at 3pm ET.

HP50/State Activities

(led by Dean Suhr, MLD Foundation)

Dean reported the first call focused on the direction this state work should take. Saira asked for groups and companies to join that, in particular, anticipate an approval of a new treatment within the next year where a good portion of their patients will be children (Medicaid will likely be a payer). Two possible work group goals discussed: advancing a specific access-related policy in states and/or coordinating, empowering, supporting groups to approach state Medicaid agencies.

Meets second Tuesdays @ 3pm

**NEW IN
2022!**

[Email Us](#)

WORKGROUPS

Meet monthly for an hour to focus on a specific topic (includes medical societies, industry, and others). Please let us know here if you'd like to join one, create one, invite others, etc. All four work groups are looking for additional interest from groups, industry, etc.

HR 6160/Medical Necessity

(led by Marc Yale, IPPF)

Marc reported their first call focused on how to build momentum for Senate Finance sponsors, and discussed setting up recess meetings with them. Marc presented slides to RDLA in March. He will videotape that for distribution and will be posted on Haystack Project's website. For those participating in Rare Across America

Meets first Wednesdays at 4:30pm ET

First Look Workgroup

This group is focused on which conditions can, at least initially, be referred out for further testing based on visual observation by a health care provider as signaling a rare condition.

Meets third Wednesdays at noon ET.

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.

