



HAYSTACK PROJECT

The Voices of Rare & Ultra Rare

YEAR IN
REVIEW **2019**

Haystack Project started its third year with clear guidance from the participating patient groups. For 2019, Members wanted to:

- 1 *Make our non-profit status official*
- 2 *Organize more in-person meetings*
- 3 *Raise HP's profile.*

Here's where we finished 2019 and where we are headed in 2020.



NON-PROFIT Status

2019

Obtained our 501(c)(3) status and Tax ID.

Although we had legal guidance on maintaining Haystack Project as an informal coalition, the participat-

ing groups were right. Non-profit status drew more patient groups to the organization. We are 60+ groups strong at year's end, and growing! Non-profit status also meant finding a CEO and establishing a Board of Directors. These positions were volunteer in 2019 and may be for one more year as we consider funding sources. We were careful to choose a Board that could provide guidance and advice, but did not have any immediate or direct financial or corporate interests in HP's work. While that has its benefits, the Board did suggest a Corporate Council, which could provide HP more direct counsel as well.

Non-profit status has also allowed Haystack Project to request sponsorships. We reached out to a very limited number of entitles in 2019 and we recognize them for their support in the pages to come.

Thank you to Hogan Lovells for their legal guidance!

IN-PERSON Meetings

2019

After 3 years of meeting almost weekly, it was great to see participating patient groups wanted to meet in person. In-person meetings

proved an effective way to cement relationships and allowed for additional networking and peer-to-peer support as Haystack transitioned to a monthly call format in 2019.

Let's face it - patient access and reimbursement issues aren't easy! As we delve into fairly arcane material, it helps to be comfortable with each other and confident in learning and discussing details together, even as we welcome new members each month. The more we learn, the more we can educate!

We held our in-person meetings when participating members were already in town for other conferences.

RARE
DISEASE WEEK
ON CAPITOL HILL



This made travel easy, and made our get-togethers cost effective.

Thank you to Hogan Lovells and Akcea for their in-kind and financial support!



RAISE OUR Profile

2019

Sharing Haystack's Mission was really rewarding!

We upped our game with policymakers and looked for opportunities to talk with other stakeholders.

MAY 2019

The **Equitable Access to Rare Disease Therapies Workshop** was a perfect opportunity to raise Haystack's profile. The *Patient Perspectives* panel not only gave us a chance to tell/hear patient stories, but to illustrate how Haystack researches the rules, regulations, laws, and incentives that drive patient care — and then sets out to educate/solve for the problem so it doesn't happen again. An empowering twist on the patient story!

DECEMBER 2019

A patient group member recommended HP as a speaker for the **Rare Disease Clinical Development & Access Summit**, and two other groups spoke about the value of their participation in Haystack. The panel on *Proactive Planning on Reimbursement* gave HP the chance to highlight the Patient Oriented Value (POV)[®] Reports we have started.



SEPTEMBER 2019

HP exhibited for the first time at **Global Genes** in San Diego in September.

One of our member patient groups designed a banner for us that was really powerful. Rare, and especially ultra-rare diseases, often go undiagnosed, unrecognized....and our banner gave every patient and caregiver



a chance to stop by, learn about our work and to add their condition to our banner. They took pictures with their families in front of the banner and posted them far and wide! What a moving experience! Yet again proving our members are our strength!

2019

While our marching orders were clearly set for 2019 by our patient groups, Haystack Project also pivoted when new opportunities presented themselves. Two in particular stand out in 2019.

RARE CANCER POLICY COALITION



First, a webinar on value frameworks sparked a conversation to think about rare cancers and their role in the rare community.



Preparations for the webinar and the work that came after led Haystack to appreciate three key realities: (i) traditionally, rare cancer groups network and identify with the cancer community; (ii) the profound connections between rare cancer issues and the rare/ultra-rare community's concerns; and (iii) the vital role cancers play in so many other rare and ultra-rare conditions.



Haystack Project invited rare and ultra-rare cancer groups to participate with them and soon found ourselves having the same interests, concerns and conversations.



The Rare Cancer Policy Coalition was born, and has since become an integral initiative of the Haystack Project. We are stronger together! And it shows in our work!



RARE DISEASE CAUCUS STAFF ROUNDTABLE



Second, one of HP's patient groups sparked Congressional interest in the concerns they were raising on Capitol Hill.



Not only did several Congressional offices agree to help, they asked if the group had ideas for possible legislative proposals to address their concerns on a larger scale.



That one group reached out to all of Haystack's groups. Pretty soon, lots of HP's patient groups began calling on their patients, medical advisors and industry partners to 'collect together' the concerns and experiences that could sensibly be turned into legislative priorities.



All this work culminated in a Rare Disease Caucus Staff Roundtable in December.



Four of Haystack's patient groups spoke on behalf of the organization on the Hill, sharing information about their rare and ultra-rare condition, their past experiences, and where legislation could play a role.

ONGOING Work

HP also continues the work it has done since

DAY 1:



We brought in **SPEAKERS**
(e.g., ICER's, new CSO)

TAUGHT & LEARNED

about various CMS proposals, ICER's methodologies and reports, HHS' Rebate rule, Congress' Drug Pricing proposals, OIG's proposed changes to the Anti-Kickback statute, and more.



EDUCATED POLICYMAKERS

where we could identify a particular concern or issue for the rare and ultra-rare community.

Thank you to Amgen for their support in allowing some of this work to continue.

While we will continue to build on the good work done over the last three years ... and will happily pivot as new and amazing opportunities come along ... we have begun another "listening tour" with our dedicated patient group participants to hear what they want to prioritize in 2020.



Find a way that suits you to help find the **"Needle in the Haystack"** as our community navigates to reimbursement that recognizes the needs of our patients, improves patient access, and leans on our patients' perspectives to define value correctly.

2020 GOALS

NON-PROFIT Status

- » Continue to cultivate new patient group members
- » Create a Corporate Council
- » Send out formal/structured sponsorship requests

IN-PERSON Meetings

- » Continue monthly calls, and create more trainings and webinars, add more guest speakers
- » Continue to hold in-person meetings

RAISE Our Profile

- » Cultivate new speaking opportunities
- » Nurture our focus on rare cancer policy
- » Continue to seek member input into Haystack's governance, structure, and direction
- » Already brought to our attention for a 2020 Goal: Solicit patient group members' support to strengthen HP's relationships with NORD, Global Genes, and EveryLife. As the only rare and ultra-rare organization that was created to focus entirely on patient access, reimbursement and value frameworks as they impact the rare and ultra-rare community, we believe our mission is clear and narrow enough to support and partner well with the other organizations.

ALONG The Way

- » Build on the Rare Disease Caucus Staff Roundtable – with a *Haystack Cures 2.0 Policy Priorities Package*

**ACT
NOW**

TO SUPPORT
OUR MISSION
AS A SPONSOR

HP has many opportunities to support our ongoing work. Choose one today.

- » Sustaining Partner \$75,000
- » Champion Partner \$50,000
- » Leading Partner \$25,000
- » Podcast Series \$5,000 - \$15,000
- » Educational Briefings \$15,000-\$25,000
- » Value Frameworks \$35,000

Request a sponsorship brochure today:

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