



Rare Cancer Policy Coalition



What is Haystack Project's

# Rare Cancer Policy Coalition?

According to NORD, there are more than 500 types of rare cancers, and all pediatric cancers are rare. So when we think of the 7,000+ rare diseases identified to date, we should be thinking about rare cancers too.

The challenges facing rare cancers are oftentimes the same as those faced by other rare and ultra-rare conditions: limited literature, few researchers, little understanding of the condition, few patients for natural history studies or clinical trials, and oftentimes the need to tackle them together. Yet rare cancer patient organizations gravitate to their **cancer** community rather than the **rare** community. In some ways, two communities are a blessing!

***Haystack's mission means rare is where rare cancers need to be!***

As the Rare Cancer Policy Coalition (RCPC) kicked off at the start of 2019, the linkages to rare were clear.

By the March Value training webinar, rare and rare cancer groups were talking to each other and finding all sorts of connections! New ideas and cross-fertilization proved true and secured RCPC in Haystack as a positive, reinforcing initiative.

So began a collaboration that continues to grow. At Global Genes, patient groups came together to recognize their rare conditions and Haystack's banner was filled with rare and rare cancer – side by side.

And that is how we now work – side by side. Calling out rare conditions and rare cancers, reinforcing the message we want policy makers to understand.

While some disease awareness and education efforts may keep rare cancers standing with their cancer community, it's clear that **Reimbursement for Rare** is a topic that should be tackled together.



What has the RCPC

# ACCOMPLISHED In 2019?

## JANUARY

- RCPC surveyed some rare cancer patient groups to understand their work on the reimbursement journey.

## FEBRUARY

- A small group of us met during Rare Disease Week to think about the possibilities of working as one.

## MARCH

- Haystack Project and RCPC members came together to participate in a webinar discussion entitled *Value - Who Defines It and Why? ...and Patient Involvement*.

## APRIL

- Haystack and RCPC Members collaborated on a comment letter to CMS.
- Members broke bread together at a dinner hosted at World Congress.

## MAY

- We came together again to write about ICER, Inpatient reimbursement, the Rebate rule and more....

## JUNE

- We spent the summer growing the number of rare cancer groups participating in RCPC
- We included outreach to oncology providers

## JULY

- Our work was recognized and highlighted in [Rare Revolution Magazine's Rare Cancer](#) edition

## AUGUST

- We worked with ASTRO to learn about the radiation oncology bundle/model and share our concerns for rare cancers.

## SEPTEMBER

- We invited Dr. Pam Bradt, ICER's CMO to a Listening Session to talk about our shared concerns for rare in ICER's methodologies.

## OCTOBER

- A dinner meeting during NORD's Summit and a congressional guest speaker cemented the reasons to work together.

## NOVEMBER

- One rare cancer group piloted a Rare Cancer Patient Oriented Value (POV)<sup>TM</sup> Report with us, setting up a 2020 survey & research project on what value means to patients.

## DECEMBER

- We jointly hosted our first Rare Caucus Staff Roundtable discussion
- ...and planned for a Senate version for 2020.



How can I

## SUPPORT & GET INVOLVED?



RCPC Supporters and Participants have an opportunity to engage by logging on to [www.haystackproject.org](http://www.haystackproject.org), checking out our work, and officially “joining” RCPC at the “Join” tab on the website.



You can also email [saira.sultan@haystackproject.org](mailto:saira.sultan@haystackproject.org) or [andra.stratton@haystackproject.org](mailto:andra.stratton@haystackproject.org) to be added to our monthly calls and social media

***One voice for Rare Access and Reimbursement for Rare!***



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*RCPC is complementary to NORD's Rare Cancer Coalition. While RCPC specifically focuses on reimbursement and access policy for rare cancers, NORD's initiative focuses on raising awareness and funding through NIH, DOD, etc. RCPC looks forward to working collaboratively with NORD.*