

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare



AEI
Advocacy Empowerment Institute

Advocacy Empowerment Institute

*Haystack participants have requested increased educational programming on a range of topics for 2021, and Haystack is responding with the **Advocacy Empowerment Institute (AEI)**. AEI is designed to cover a range of topics, recognizing that rare and ultra-rare organizations are often required to be experts in many things, from governance and fundraising to translating complex healthcare policies into patient-centric advocacy concepts. Seemingly daunting topics will be made both approachable and more readily integrated into the operations and mission of the participant groups.*

Background

Haystack was founded on the core principle of educating its participants about healthcare policies that create barriers to rare therapies access while simultaneously learning about the impact those barriers have in lives of patients, families, and caregivers. This give-and-take has always insured participants are at the center as essential stakeholders in their health care journeys.

AEI is a logical extension of Haystack's mission in that it will provide:

INSIGHTS

into the framework and mechanisms of how healthcare delivery works;

ESSENTIAL INFORMATION

about the impact different stakeholders have on access;

UNDERSTANDING

of how to engage levers that impact the changes/advances participants seek;

APPROACHES

to growing their organizations *to advance their missions.*

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare



AEI
Advocacy Empowerment Institute

AEI Objectives

The first offering is a curated, moderated, and interactive 12-part course. It will help participants develop the skill set and requisite understanding of how to actively engage the processes and stakeholders necessary to advance their cause and strengthen aspects of their own organizations. Individuals will leave the course with the tools and techniques necessary to make them effective advocates and to more readily integrate concepts into the operations and missions of each organization.



AEI Content

INSTITUTE FELLOWS.

AEI will work with experts in different healthcare segments to develop content and lead learning modules that are user-friendly and geared to meeting the groups where they are, ensuring the content is actionable for participants.

COURSE STRUCTURE.

Course participants will come together virtually on a periodic basis for 12 classes. Pre-reading and/or multi-media resources will be provided to enhance the subject material. All classes will include segments designed for open dialog and questions and answers with instructors and moderators. All classes will be recorded.

COURSE CONTENT.

Participating groups have informed topic selection for the 12-part course. A first session was piloted in Dec. 2020 on the Patient Centered Outcome Research Institute's (PCORI's) grants, their availability, criteria, and structure. 30+ groups found the pre-read, presentation, and discussion extremely helpful.

HAYSTACK PROJECT

The Voices of Rare & Ultra Rare



AEI
Advocacy Empowerment Institute

Haystack Project plans to include additional topics identified by participating groups, including:

GAO

What is the Government Accountability Office? How can it provide a “beach head” for an organization’s goals?

HEALTH EQUITY

How relevant is the current emphasis on health equity when it comes to ultra-rare conditions and how can groups do something meaningful for their patients?

ICER

Institute for Comparative Effectiveness Research – An Economist’s View.

MEDICAID

How has the skyrocketing trend to managed care impacted patients?

GOVERNANCE & FUNDRAISING

Without the basics, true value is waiting to be unlocked.

ENGAGEMENT / GRASSROOTS

“How to Talk to Pharma” – a repeatedly requested topic!

UTILIZATION MANAGEMENT

How can case studies in reducing the provider burden of utilization management be applied to rare and ultra-rare conditions?

PCORI 2.0

A follow-on to the pilot PCORI presentation has already been requested by the groups who attended in Dec. 2020. There is strong demand to learn the mechanics of grant requests centered on the congressionally mandated focus on rare diseases.





HAYSTACK PROJECT

The Voices of Rare & Ultra Rare



AEI
Advocacy Empowerment Institute

Upon completion of this course, participants will be able to:

-  Chart a course to a PCORI grant or a GAO study
-  Evaluate third party stakeholders to support their missions/goals
-  Better articulate their partnership requirements
-  Organize workstreams to meet their patients' needs

Participant feedback will be sought throughout the course to assess understanding, need for follow-up, additional courses/speakers. This course will be provided to participants at **NO COST**.

ABOUT the Haystack Project

The **Haystack Project** is a non-profit coalition (501(c)(3)) enabling its over-70 participating rare and ultra-rare disease patient advocacy organizations to highlight and address systemic reimbursement obstacles to patient access through focused, unified education and outreach strategies.