



# Rare72

Sourcing solutions for rare disease.

72 HOURS. 1 COMMUNITY. 1 GOAL.

## STEP 01

### Stakeholder Identification

- Patients
- Caregivers
- Physicians/Providers/Hospital Systems
- Researchers
- Non-profit organizations
- Advocates
- Industry
- Payers
- Educational Support

Before the event opens, participants gather general or disease state-specific resources for upload to the Rare72 platform. These resources could include anything from clinical pathways to legislative concerns and patient assistance programs to accessibility issues.

While any type of resource may be uploaded, every submission will be vetted using Medline Plus standards.

### Rare72 Launch

- Day One - Live kickoff meeting
  - Moderated asynchronous discussion begins on the platform/Submission reporting goes live
- Day Two - Live progress meeting/updates
- Day Three - Wrap Initial 72 hours, post-event surveys sent

Using an independent assessment tool that follows guidelines issued by recognized leaders like MedLinePlus and the National Institutes of Health, every submission is blinded and the veracity of every resource is evaluated.

The review panel is comprised of recognized experts from the academic, patient and research communities.

### Reporting & Next Steps

Prior to the launch of a Rare72 Cycle, participants are invited to complete pre-event surveys based on the stakeholder group they selected at registration. These surveys are designed to not only provide a current "state of the disease" picture but to highlight common resources for the population while identifying stakeholder goals and existing gaps for further assessment.

## STEP 02

### Stakeholder Prep

- Standards of Care/Centers of Excellence/Registries/Natural History Studies
- Treating Physicians
- Online Support Groups
- Non-Profit Organizations
- Researchers/Published Studies
- Labs/Current projects
- Product Development
- Patient Assistance
- Legislative awareness/updates

## STEP 03

The Rare72 platform opens! For 72 hours, global stakeholders share resources, meet with other stakeholders and engage in discussions while submissions are cataloged in real-time. Rare72 teams begin their challenge work.

Status meetings are held throughout the event and post-event surveys are sent.

## STEP 04

### The Analysis

- Source/age of data/resource
- Application of the resource in the current disease state
- Credibility of source
- Supporting evidence
- Intention of the resource
- Review of process
- Observance of GDPR/FDA regulations

## STEP 05

- Final report issued to stakeholders
- Annual review of resources conducted

