



# ASPIRE

## Annual Report 2025



# Contents

---

## **About ASPIRE | Page 3**

Established in 2021, the collective convenes leading companies in a pre-competitive space to address some of the most urgent issues faced by the amyloidosis community.

## **A Note From Our Chairs | Page 4**

ASPIRE delivered meaningful impact across three working groups and welcomed new member companies, strengthened governance, and deepened engagement.

## **2025 In Review | Page 5**

Last year was a year of growth and execution. 2026 will be a year of scale, refinement, and sustained impact.

## **Coordinated Care Working Group | Page 6**

Creating systems of coordinated care to enhance knowledge-sharing, expand support networks, reduce access barriers, and improve patient care and well-being—especially in regions without easy access to Specialized Amyloidosis Centers.

## **Diagnostic Pathway Working Group | Page 7**

Dedicated to understanding and improving how patients with amyloidosis are diagnosed. Working to uncover barriers and highlight best practices to inform timely and equitable care.

## **Health Equity Working Group | Page 8**

Seeking to better understand the consequences of differential treatment and identify opportunities to apply practical, effective, systematic solutions that move the amyloidosis community toward health equity.

## **ASPIRE Member Companies | Page 9**

Nine organizations collaborating in the pre-competitive space to create significant, impactful change to benefit amyloidosis patients and families around the world.

## **Committee and Working Group Members | Page 10**

The champions and advocates behind the studies, surveys, meetings, and working sites pushing the amyloidosis community forward in care, diagnosis, equity, and collaboration.

# About ASPIRE

ASPIRE's mission is to collectively power inclusive and accessible solutions in partnership with the broader amyloidosis community to improve quality of life and health outcomes

**ASPIRE:**  
Amyloidosis  
Stakeholder  
Partnerships for  
Impact, Reach  
and Equity

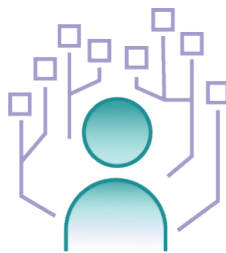
## Focus

Accelerate progress in the areas of diagnosis, care, and address health disparities through collaborative project design and shared resources, arriving at solutions that address common challenges and unmet need.

## Initiatives



**Coordinated Care  
Working Group**



**Diagnostic Pathways  
Working Group**



**Health Equity  
Working Group**

# A Note From Our Chairs

---

Dear Colleagues, Partners, and Friends,

As we reflect on 2025, we are proud to share the remarkable progress ASPIRE has made in advancing our shared mission: improving diagnosis, expanding access to care, and addressing health disparities for patients living with amyloidosis. Since our inception in 2021, ASPIRE has grown into a powerful collaborative platform, proving what is possible when industry leaders unite in a non-competitive environment to tackle the most pressing challenges in rare disease care.

This year, ASPIRE delivered meaningful impact across our three working groups:

- **Coordinated Care:** Finalized the framework for regional amyloidosis care networks and launched Amyloidosis PROJECT ECHO, a virtual education model connecting specialists with community providers to reduce barriers to care.
- **Diagnostic Pathways:** Initiated a groundbreaking project to map the patient journey, building on our 2024 publication and reviewing the role of technology and AI to better understand the barriers and breakthroughs in diagnostic pathways for patients.
- **Health Equity:** Completed a Cincinnati focus group study to capture the lived experiences of Black Americans with amyloidosis, informing practical solutions to promote equity in diagnosis and treatment.

Beyond these achievements, we welcomed new member companies, increased the number of participants, strengthened governance, and deepened engagement through in-person and virtual collaboration. Together, we have demonstrated that collective action drives meaningful change for patients and families affected by amyloidosis.

As we look ahead, ASPIRE remains steadfast in its vision: accelerating progress through partnership, innovation, and equity. We are grateful to each of you — our member companies, working group leaders, and ARC colleagues — for your dedication and passion. The work we do together is transforming lives, and as we head into 2026, we are excited for what we will accomplish in the years to come.

Thank you for your continued commitment to ASPIRE and the amyloidosis community.

With appreciation,

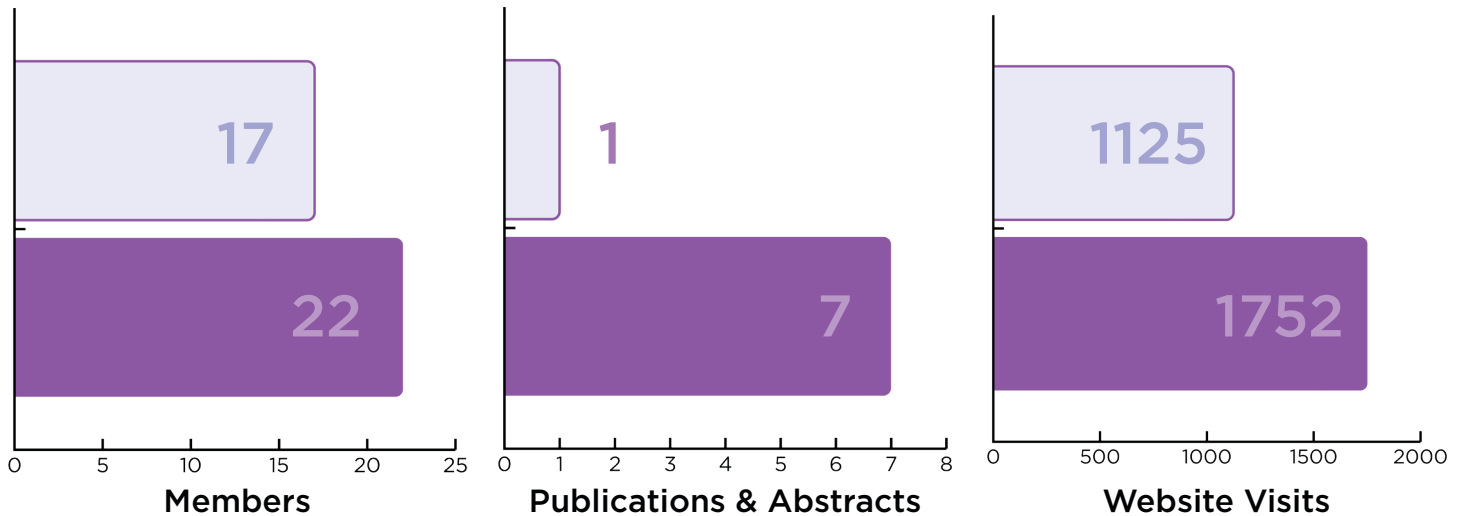
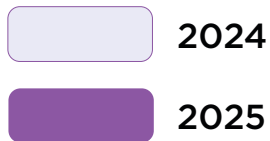
Kaushik Ghosal, Chair, ASPIRE Executive Steering Committee  
Nis Kumar, Co-Chair, ASPIRE Executive Steering Committee

# 2025 In Review

Growth, Progress, and Impact



# ASPIRE



New Branding and Webpage



Presentation at NORD Meeting



Project ECHO Launched



Annual In-Person Meeting

**2025 delivered growth and execution.  
2026 is poised to bring scale, refinement, and sustained impact.**

# Coordinated Care Working Group

## 2026 Plans:

Grow Amyloidosis Project ECHO

Publish additional findings

Refine regional care network model

## Overview

This group works to create systems of coordinated care to enhance knowledge sharing, expand support networks, reduce access barriers, and improve patient care and well-being.

Building on a foundational survey conducted from 2023-2024, the Coordinated Care Working Group advanced its mission in 2025 by transforming insights into actionable programs and expanding knowledge-sharing across the amyloidosis care community.

## 2025 in Review

### American Association of Heart Failure Nurses (AAHFN) Poster Presentation

Evidence-based insights from a Best Practices Survey conducted by the working group shared with a national audience to increase awareness of innovative approaches that directly impact patient care.

### American Society of Clinical Oncology (ASCO) Abstract Presentation

Dr. Jose Nativi-Nicolau of Mayo Clinic presented best practices and key barriers for light chain (AL) amyloidosis patient care at US specialized amyloidosis centers to influence clinical dialogue and future research.

### Amyloidosis Project ECHO Launch

A collaborative learning model for medical education that enables expert healthcare teams to provide best-practice education to non-specialist healthcare providers around the world through case-based learning.



44

Registrants

8

Countries

25

Participants

# Diagnostic Pathways Working Group

2026 Plans:

Mapping the patient journey

ID diagnostic delays & regional disparities

Develop actionable recommendations

## Overview

With diagnosis often delayed 1-3 years due to non-specific symptoms, low awareness, and limited access to testing, the Diagnostic Pathways Working Group examined how patients move from suspicion to diagnosis in 2025.

Building on AI-centered efforts, the group launched a multi-year real-world analysis to map patient journeys and identify delays, disparities, and fragmentation.

## 2025 in Review

### AI White Paper

The working group produced a comprehensive, expert-driven white paper outlining real-world adoption challenges, opportunities, and best practices for AI in cardiac amyloidosis.

The paper provides practical guidance for responsible tool development and accelerated, meaningful clinical use.

### Amyloidosis Claims Study

A targeted claims analysis examining regional variation in diagnosis and treatment of amyloidosis was launched in 2025.

The study is collecting evidence to inform more equitable care pathways and support earlier, more accurate disease detection.

### American Heart Association Journal Publication

The working group published a peer-reviewed narrative review in a leading cardiovascular journal, demonstrating strong engagement, visibility, and early influence within the cardiovascular and research communities.



American Heart Association.

3800+

Downloads

5

Citations

11

Authors

# Health Equity Working Group

## 2026 Plans:

Submit insights into patient voice and health equity

Launch case study examining AL & Female ATTR patient experiences across U.S.

## Overview

The group continued its pivotal work in 2025 by expanding efforts to better understand disparities and implement systemic solutions in amyloidosis care.

After implementation of a Cincinnati-area case study, the group has refined its analysis and deepened community engagement. The group remains focused on identifying differential treatment consequences and deploying practical, effective, systemic solutions that advance health equity in the amyloidosis community.

## 2025 in Review

### Focus Group

The working group convened an in-person focus group in Cincinnati to evaluate the lived experiences of Black Americans affected by amyloidosis.

The work generated qualitative insights that are often underrepresented in rare disease research.

### Initiated a Trend Case Analysis

The working group launched a follow-up study to its Cincinnati, Ohio focus group that is focused on social determinants of health in Black AL patients and Female ATTR patient experiences across different geographical regions in the United States.

### Equity-Focused Manuscript Development

The group is currently finalizing a manuscript for submission detailing insights to advance the integration of patient voice and health equity considerations into the broader rare disease evidence base.



# ASPIRE

# ASPIRE Member Companies



BridgeBio is truly grateful for our partnership with ASPIRE ... By bringing our shared commitment and focus together, we're not just collaborating, we're accelerating real progress for the patients and families counting on us. We're proud to stand with ASPIRE and energized by what we will continue to accomplish together.

— BridgeBio



As a member of ASPIRE, we are proud to contribute to a shared mission of increasing recognition of ATTR amyloidosis, enabling earlier treatment, and improving outcomes for patients.

— Anylam Pharmaceuticals



Through ASPIRE, we are demonstrating the impact of cross-industry collaboration united by a shared purpose: to improve the patient journey in amyloidosis ... ASPIRE is helping to drive meaningful, actionable change for patients and the broader amyloidosis community.

— Ionis Pharmaceuticals

# Executive Steering Committee



**Kaushik Ghosal**  
Amyloidosis Research Consortium (ARC)  
Chair



**Nisith Kumar**  
Pfizer  
Co-Chair



**Jocelyn Ashford**  
AstraZeneca  
Health Equity Working Group



**Alexandra Haddad Angulo**  
Pfizer  
Coordinated Care Working Group



**Colleen Moffitt**  
Alnylam  
Coordinated Care Working Group



**Spencer Guthrie**  
Attralus  
Diagnostic Pathways Working Group



**Veena Narayan**  
Ionis  
Diagnostic Pathways Working Group



**JeShaune Jackson**  
BridgeBio  
Health Equity Working Group

## Working Group Members

### Coordinated Care Working Group

Colleen Moffitt, PharmD, MS (Alnylam) — Co-Chair  
Alexandra Haddad Angulo, MD (Pfizer) — Co-Chair

Nis Kumar (Pfizer)  
Alyssa Galloway (Bridge Bio)  
Gabriela Tamariz (Alnylam)  
Tina Gerbek (Novo Nordisk)  
Karthik Veera (Prothena)  
Pamela Vynalek (Bridge Bio)

### Diagnostic Pathways Working Group

Spencer Guthrie (Attralus) — Co-Chair  
Veena Narayan (Ionis) — Co-Chair

Nis Kumar (Pfizer)  
Alice Yu (AstraZeneca)  
Lori Baylor (Pfizer)  
Edgar Vega (Bridge Bio)

### Health Equity Working Group

Jocelyn Ashford (AstraZeneca) — Co-Chair  
JeShaune Jackson (BridgeBio) — Co-Chair

Nis Kumar (Pfizer)  
Karen Ross (Prothena)  
Courtney Ijeoma (Alnylam)  
Victoria Sanjurjo (Ionis)  
Tessa Field (Intellia)  
Pooja Desai (AstraZeneca)  
Jess Kachadourian (Intellia)  
Robert Gibson (Amyloidosis Support Groups)



# ASPIRE

Amyloidosis Stakeholder Partnerships for  
Impact, Reach and Equity

---

For more information about ASPIRE:  
[arci.org/aspire](http://arci.org/aspire)