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# ASPIRE

Amyloidosis Stakeholder Partnerships  
for Impact Reach and Equity

Annual Report  
**2024**

# About ASPIRE

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Established in 2021 by the Amyloidosis Research Consortium (ARC), ASPIRE: Amyloidosis Industry Collaborative convenes leading companies in a non-competitive environment to address some of the most urgent issues faced by the amyloidosis community. Through partnership we are driven to shift the discourse and demonstrate what can be done when leaders work together on behalf of rare disease patients.

ASPIRE seeks to enhance advancements in diagnosis, care, and the reduction of health disparities by fostering collaborative project design and sharing resources. This initiative aims to create solutions that tackle shared challenges and unmet needs.

ARC and ASPIRE member companies are dedicated to integrating diverse viewpoints and experiences in the development and execution of solutions. Our collaborative strategy is crucial for recognizing and addressing the community's unmet needs, ultimately creating a meaningful impact for patients.

**“Given the unmet needs of Amyloidosis patients, I am pleased with the progress of our collective efforts. I’m inspired by the passion and focus of our industry and ARC colleagues to address these challenges. We are starting to demonstrate our impact across all three working groups, and we are well positioned to make tangible contributions to the Amyloidosis community in the coming years.”**

**— Nis Kumar, Pfizer, Inc, ASPIRE Executive Steering Committee Chair**

## ASPIRE Member Companies



# A Year in Review

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2024 was an exciting year for ASPIRE!

All three Working Groups — Coordinated Care, AI, and Health Equity — focused on significant projects aimed at transforming the lives of patients affected by Amyloidosis.

## Additional Activities to Highlight in 2024:

- **In-person Meeting:** The ASPIRE Members gathered in Boston for their annual in-person meeting, which served as a valuable platform for engaging discussions among participants.
- **New Member:** Intellia Therapeutics has become a part of the ASPIRE group and will be partnering with the Health Equity Working Group.
- **ARC's Increased Commitment:** ARC has welcomed two new team members who will collaborate closely with ASPIRE: Kaushik Ghosal, the Director of Business Development and Strategic Partnerships, and Megan Glynn, the Senior Program Manager for ASPIRE.

# Coordinated Care Working Group

From December 2023 to February 2024, the Coordinated Care Working Group carried out a survey aimed at understanding best practices and obstacles faced by Specialized Amyloidosis Centers (SACs) in the United States. This survey yielded valuable responses from 50 healthcare providers across 17 SACs, 21 patients diagnosed with ATTR amyloidosis or AL amyloidosis, along with 3 referring physicians and 3 patient advocacy groups.

Following the survey, the group has discovered creative methods to disseminate these findings, including:

- ✓ The Coordinated Care Working Group showcased a poster at the 2024 Annual Conference of the International Society of Amyloidosis (ISA).
- ✓ The group has submitted two additional abstracts to present findings in 2025.
- ✓ The working group has prepared a manuscript detailing their findings and will also produce a Plain Language Summary of the survey results.



## Mission

Creating systems of coordinated care to expand knowledge-sharing and extend networks of support, elevate the care received by patients, reduce barriers to seeking healthcare, and strengthen additional aspects of health and social well-being.



## Goals

Develop a framework, key considerations, criteria, and best practices for coordinated care and regional care network models.

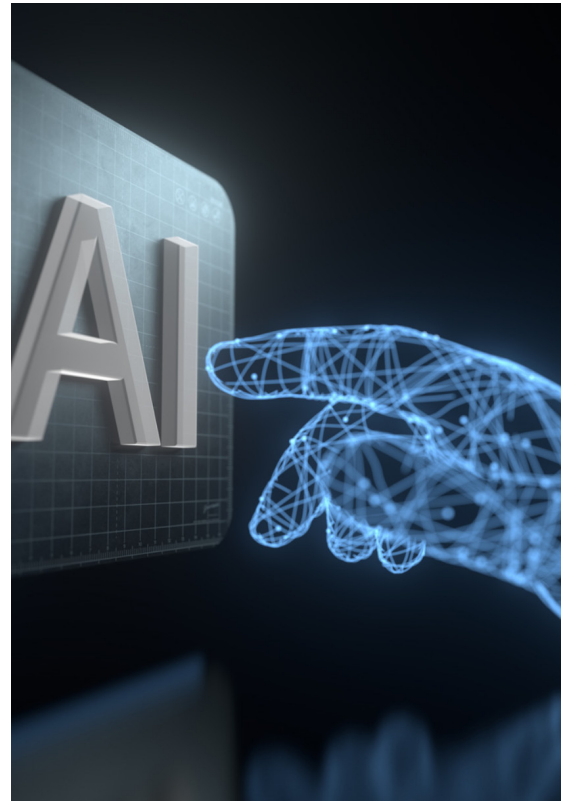
**“In 2024 the ASPIRE Coordinated Care Working group has focused on enhancing amyloidosis care coordination through identification of best practices and barriers in the diagnosis and management of all types of amyloidosis. To further our efforts to enhance accountability, improve communication, and resources alignment in amyloidosis care, we are developing a case-based discussion platform to facilitate knowledge sharing among providers involved in amyloidosis care, with particular focus in regions of the country with greatest need.”**

**— Alexandra Haddad, MD, Pfizer Inc. and Collen Moffit, Alnylam Pharmaceuticals, ASPIRE Coordinated Care Working Group Chairs**

# AI Working Group

The AI Working Group had a productive year, focusing on evaluating the current AI tools being developed for Amyloidosis while also discussing the limitations and best practices within the field.

- ✓ The group worked with top experts in the field to write and publish the manuscript, *The value of artificial intelligence for enhancing suspicion of cardiac amyloidosis using electrocardiography and echocardiography: A narrative in the Journal of the American Heart Association*.
- ✓ After finishing an advisory board in late 2023 with nine experts in Amyloidosis, the working group produced a white paper detailing the findings from the advisory board.
- ✓ In 2025, the group will embark on a new path and initiate a project focused on the journey of patients with Amyloidosis.



## Mission

To Improve the diagnosis of cardiac amyloidosis using AI-based solutions



## Goals

Support the AI/cardiac amyloidosis community to unlock the broader value of AI by identifying opportunities and current limitations for broader implementation of AI tools and informing best practices on broad implementation of AI tools

**“The use of AI in imaging for cardiac amyloidosis may lead to earlier diagnosis, which may improve outcomes for patients. The ASPRIE team worked with experts in cardiac amyloidosis and AI experts to determine gaps in the current development and key next steps in improving the use of AI.”**

— Spencer Guthrie, Attralus, ASPIRE AI Working Group Chair

**“In this rapidly advancing field, our team is proud of the strides we’ve made in exploring AI’s role in cardiac amyloidosis and hope our work will serve as a guiding framework for improving patient care. In 2025, we will expand our impact to focus on mapping the complexities of the patient journey. ”**

— Lori Baylor, PhD, Pfizer, ASPIRE AI Working Group Chair

# Health Equity Working Group

The Health Equity Working Group has committed 2024 to fostering a significant conversation about amyloid diseases. The goal is to document the conditions, treatment options, barriers, and needs of Black Americans in Cincinnati who are living with Amyloidosis.

- ✓ The team started collaborating with The Voice of Your Customer, a Black-owned and minority-certified marketing consulting firm dedicated to reaching underserved communities and connecting with Black Cincinnatians diagnosed with amyloidosis.
- ✓ The team is organizing a full-day focus group in Cincinnati, Ohio, aimed at gaining insights into the experiences of adult Black Americans residing or working in the Cincinnati area who have been diagnosed with either light chain amyloidosis (AL) or transthyretin amyloidosis (ATTR).



## Mission

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



## Goals

Understand, through a focus group, the lived experiences of adult, Black Americans living and/or working in the Cincinnati area who have been diagnosed with either light chain amyloidosis (AL) or transthyretin amyloidosis (ATTR).

**“Addressing the challenge of disparate care begins with truly understanding the problem from the perspective of the impacted; and it energizes me to have the chance to be part of ASPIRE, where we have a shared intent, passion and dedication to do just that.”**

**— Jocelyn Ashford, AstraZeneca, ASPIRE Health Equity Chair**

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Amyloidosis  
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Consortium

For more information about ASPIRE, please visit: [arci.org/aspire](https://arci.org/aspire)