

# ARC TALKS

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WEBINAR SERIES

## Coffee Chat with ARC

December 18 | 12pm ET



### The ARC Team

Members of the Leadership, Research,  
Development, Communications,  
and Community Alliance Teams

**ARC's mission is to improve and extend the lives of those with amyloidosis**

## OUR FOCUS

**IMPROVING**  
the speed and  
accuracy of  
diagnosis

**INCREASING**  
our understanding  
of the genetics,  
biology and  
natural history  
of amyloidosis  
to identify new  
treatments

**ACCELERATING**  
regulatory  
approval and  
reimbursement  
of effective  
treatments for  
patients

**ENHANCING**  
care and quality  
of life of patients  
and caregivers  
throughout their  
amyloidosis  
journey

# ARC Talks Supported By



# Before We Begin



This webinar is recorded. We will post the webinar on our website so you can view it again later.



Submit your questions anytime via the Q&A box. We will try to answer them at the end.



If you are having trouble with the audio using your computer, you can dial in (check your email for info).



# Patient Support & Education

## Navigating the Patient Journey

## Patient Journey

- Why does someone call?
  - Emotional support
  - Disease and treatment information
  - Insurance and financial assistance
  - Treatment center/clinical trials
  - Community resources
- What can ARC support with?
- What happens next?

## Patient Support, Education and Resources

- PEER Link
- Website
  - Newly Diagnosed
- ARC Talks
- Informational Booklets

[support@arci.org](mailto:support@arci.org) | 617-467-5170

# ARC Resources: Booklets



## KNOWLEDGE IS POWER



### Learn about Amyloidosis

ARC has developed a comprehensive range of booklets focusing on different types and aspects of amyloidosis. These booklets are written specifically for patients and provide information to help you gain a better understanding of the disease, treatment options, and ways to manage common side effects. They are available digitally on the [ARC website](#). We would be delighted to send you a copy of these booklets as well. To get yours, use the request form below.

[REQUEST YOURS HERE »](#)



Amyloidosis Research Consortium | 10 YEARS

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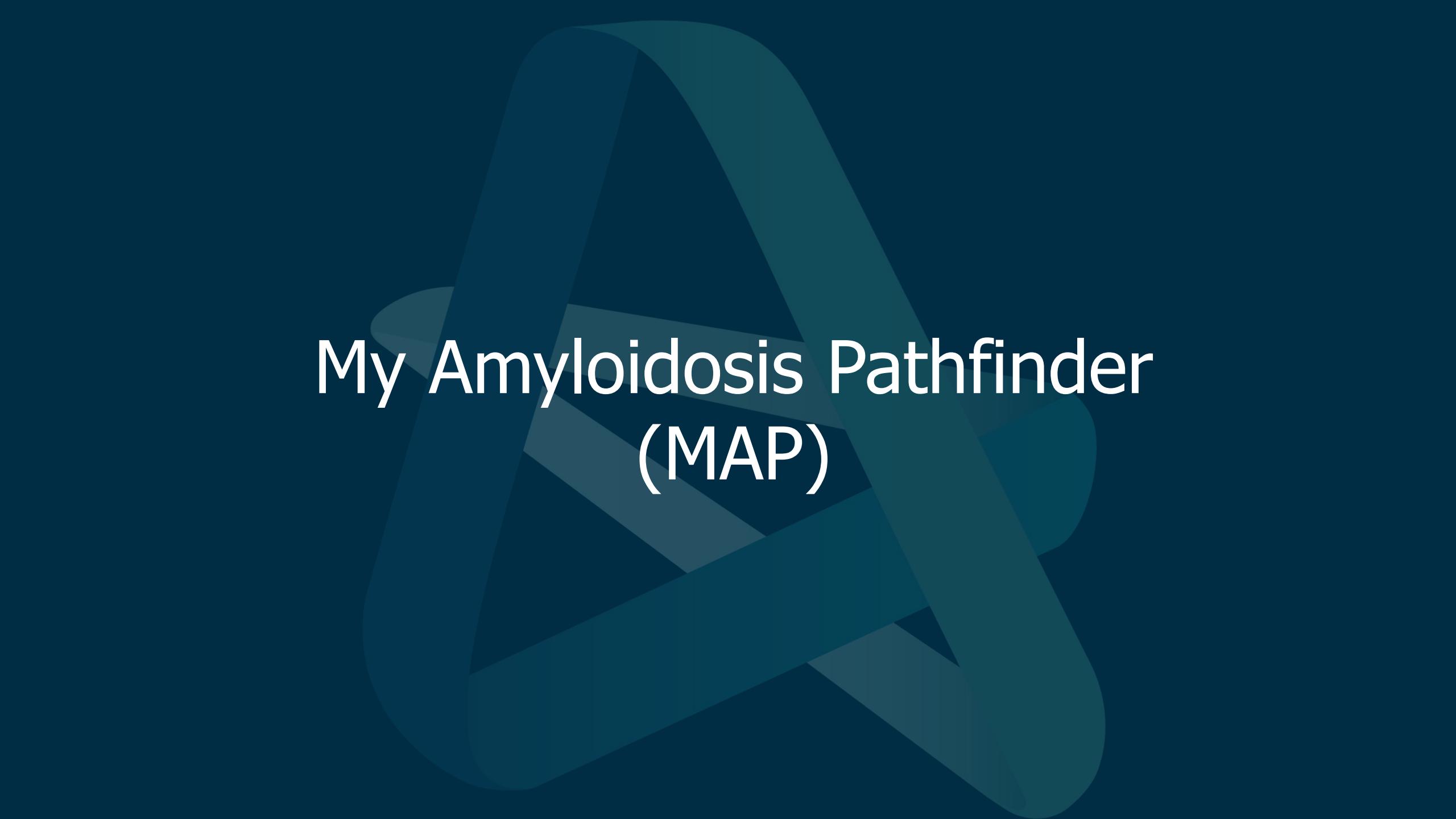
Amyloidosis & Types | Care & Support | Providers & Research | Get Involved | About ARC

# New to Amyloidosis

We're here to help you take the next steps in your amyloidosis journey.

Amyloidosis Overview | Types of Amyloidosis | Next Steps in Managing Your Care

TALK TO US: (617) 467-5170 | support@arci.org



# My Amyloidosis Pathfinder (MAP)

# ARC Clinical Fellowship Program



The Clinical Fellowship in amyloidosis is a specialized training program aiming to cultivate expertise in the diagnosis, management, and research of amyloidosis, fostering multidisciplinary collaboration and addressing health disparities for the next generation of healthcare professionals



# Clinical Fellowship Institutional Requirements



- Mentors/Centers with strong amyloidosis experience
- Thriving research environment
- Expertise in clinical care & support
- Exposure to diverse populations

# Clinical Fellowship Goals

- **Expertise and Specialized Training:** Provide specialized training in the diagnosis, classification, and management of amyloidosis. Ensure exposure to diverse cases, advanced diagnostic techniques, and cutting-edge treatment modalities to cultivate expertise in this complex field.
- **Multidisciplinary Collaboration:** Promote interdisciplinary collaboration by facilitating interactions between fellows and experts from various medical specialties involved in the comprehensive care of amyloidosis patients. Enhance communication and teamwork to provide holistic and patient-centered care.
- **Outreach and Education:** Engage in conferences, exchange programs and collaborative research initiatives, contributing to a broader understanding of amyloidosis on a global scale.
- **Health Equity Initiatives:** Address healthcare disparities in amyloidosis diagnosis, treatment and outcomes among minority populations.

# ARC Clinical Fellowship Program



## 2025-2026 Awardees

**Boston Medical Center** (Mentor - Vaishali Sanchorawala, MD)

**Columbia University** (Mentor - Mathew Maurer, MD)

**Mass General Brigham** (Mentor – Hanna Gaggin, MD)

**Northwestern University** (Mentor – Sanjiv Shah, MD)

**Oregon Health & Science University** (Mentor – Ahmad Masri, MD)

**University of Chicago Hospitals & Endeavor Health System** (Mentor – Nitasha Sarswat, MD)

**University of Texas Southwestern Medical Center** (Mentor – Justin Grodin, MD)

# The Forum Meeting



## 2026-2027 Awardees

- **Amyloidosis Program of Calgary** (Mentor – Victor Zepeda, MD)
- **Cleveland Clinic – Ohio** (Mentor – Mazen Hanna, MD)
- **Columbia University** (Mentor–Mat Maurer, MD, Eugene Brailovsky, MD & Karan Wats, MD)
- **Mass General Brigham** (Mentor – Hanna Gaggin, MD & Sarah Cuddy, MD)
- **Memorial Sloan Kettering** (Mentor – Heather Landau, MD)
- **Northwestern University** (Mentors – Sanjiv Shah, MD & Ike Okwuosa, MD)
- **Oregon Health & Sciences University** (Mentor – Ahmad Masri, MD)
- **Stanford University** (Mentor – Kevin Alexander, MD)
- **University of Chicago** (Mentor – Nitasha Sarswat, MD)
- **UT Southwestern** (Mentor – Justin Grodin, MD)



# ASPIRE

Amyloidosis Stakeholder Partnerships for  
Impact, Reach and Equity

December 18, 2025

## OVERVIEW

# ASPIRE – Partnership of Pharma and Biotech companies in Amyloidosis



Established in 2021, the ASPIRE: Amyloidosis Industry Collaborative convenes leading companies in a **pre-competitive space** to address some of the most urgent issues faced by the amyloidosis community.



## PROVIDE A FRAMEWORK FOR COLLABORATION

Companies partner on key initiatives to advance the field; addressing significant challenges that would benefit greatly from cooperative solutions



## MAXIMIZE AVAILABLE RESOURCES

To drive efficiency, coordinate efforts in critical areas, address unmet needs in the community, and accelerate meaningful progress for patients

# FOCUS AREAS



## Coordinated Care

Create systems of coordinated care to enhance knowledge-sharing, reduce access barriers, and improve

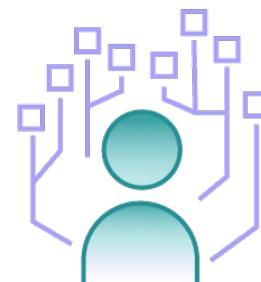
patient care



## Diagnostic Pathways

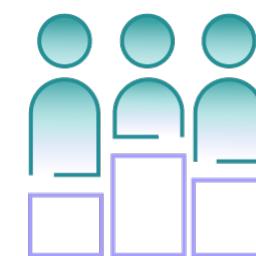
Understand and improve barriers to diagnostic journey and highlight best practices to inform timely and equitable

care.



## Health Equity

Identify opportunities to apply practical, effective, systematic solutions that move the amyloidosis community toward health equity.



# Highlights to date

## ASPIRE

Amyloidosis Stakeholder Partnerships for Impact Reach and Equity

2021

### AI/Diagnostic Pathways Ad Board

Artificial Intelligence/Diagnostic Pathways Working Group holds Advisory Board on AI Solutions in Cardiac Amyloidosis

### Coordinated Care Working Group Best Practices Survey

Coordinated Care launched a Best Practices in Specialized Amyloidosis Centers Survey

### White Paper

The AI Working Group created a white paper based on their advisory board findings



### ASPIRE Rebranding

ASPIRE completed a rebranding that includes a new logo and webpage update

Artificial intelligence in cardiac amyloidosis: Expert insights on adoption challenges, opportunities and best practices for developing effective tools

Francisco Lopez-Jimenez, MD; Faraz Shafique Ahmad, MD; Gary Woodward, BSc (Hons) PhD, MSc; Lori Baylor, PhD; Nithi Kumar, MBA; Spencer Guthrie, MBA; Veena Narayan, PhD; David Dwyer, MD



### Presentation at AAHFN

The CCWG Presented an ENCORE Poster at the AAHFN Annual meeting

### Best Practices Manuscript

The CCWG Working Group submitted a manuscript based on survey findings.

### Inception

Concept brought to ARC to provide platform for Industry/ Cross- Stakeholder Collaboration in the pre-competitive space

### Working Groups Formed

Working groups formed to develop programs in 3 key areas, and the first in-person meeting at ISA in Heidelberg.

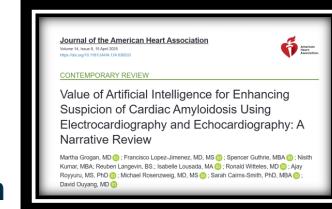


### ISA Presentation

CCCWG showcased a poster at the 2024 Annual Conference of the International Society of Amyloidosis (ISA).

### 1st Annual Impact Report

First ASPIRE Impact Report published



### JAHAA Publication

The AI Working Group's manuscript published in the Journal of the American Heart Association.

### Health Equity Focus Group

The Health Equity working group conducted a focus group in Cincinnati, Ohio and began a manuscript based on findings



ASPIRE



### NORD Breakthrough Summit

ASPIRE Model Presented at NORD Annual Meeting

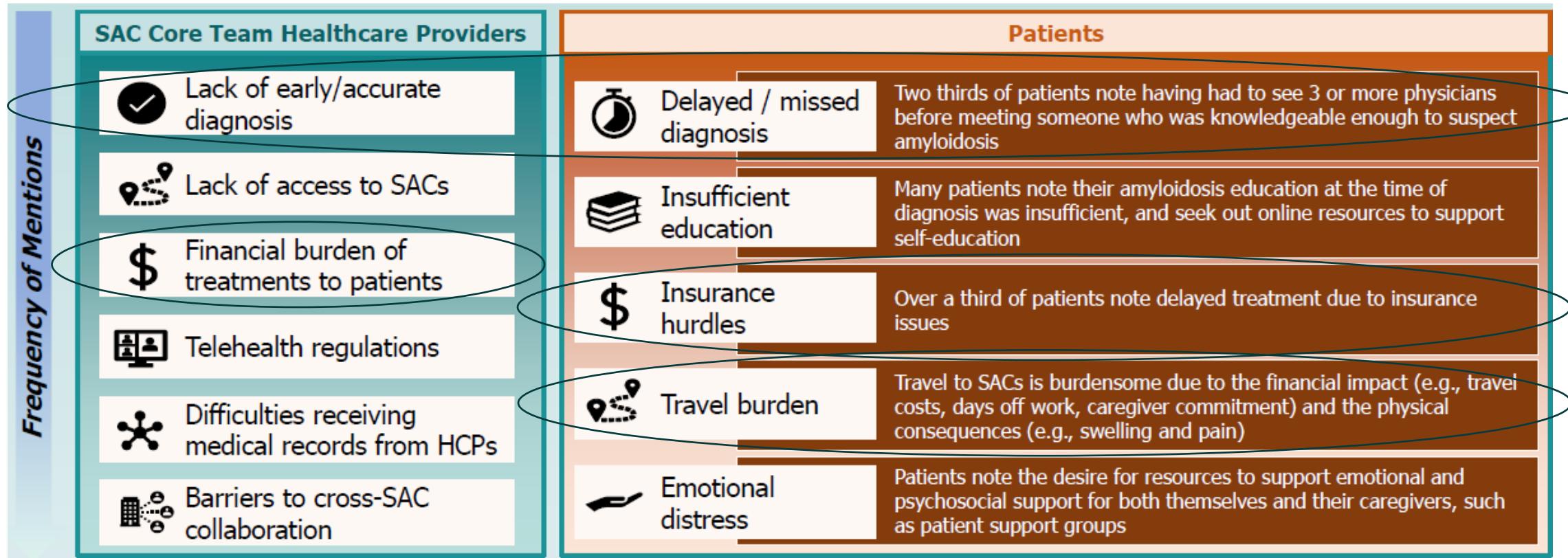


### Amyloidosis Project ECHO Launch

Coordinated Care Working Group will launch an Amyloidosis Project ECHO

# Best Practices and Key Barriers for Amyloidosis Patient Care at US Specialized Amyloidosis Centers – an Analysis by ASPIRE

Jose Nativi-Nicolau<sup>1</sup>, Johana Fajardo<sup>2,11</sup>, Alyssa Galloway<sup>3,11</sup>, Sami Khella<sup>4</sup>, Nisith Kumar<sup>5,11</sup>, Reuben Langevin<sup>6,11</sup>, Michaela Liedtke<sup>7</sup>, Isabelle Lousada<sup>6,11</sup>, Tiffany Patrick<sup>8,11</sup>, Gabriela Tamariz<sup>8,11</sup>, Karthikeyan Veeraraghavalu<sup>9,11</sup>, Lori Klein<sup>10</sup>, Alexandra Haddad-Angulo<sup>5,11</sup>  
Affiliations: <sup>1</sup>Mayo Clinic, <sup>2</sup>Duke University Hospital, <sup>3</sup>BridgeBio, <sup>4</sup>Penn Medicine, <sup>5</sup>Pfizer Inc., <sup>6</sup>Amyloidosis Research Consortium (ARC), <sup>7</sup>Stanford Health Care, <sup>8</sup>Amylam Pharmaceuticals, <sup>9</sup>Prothena Biosciences, <sup>10</sup>Putnam, <sup>11</sup>Amyloidosis Stakeholder Partnerships for Impact, Reach & Equity (ASPIRE)



**Lack of early/accurate diagnosis continues to emerge as one of the most common perceived barrier to care in amyloidosis.**

# Amyloidosis Project ECHO

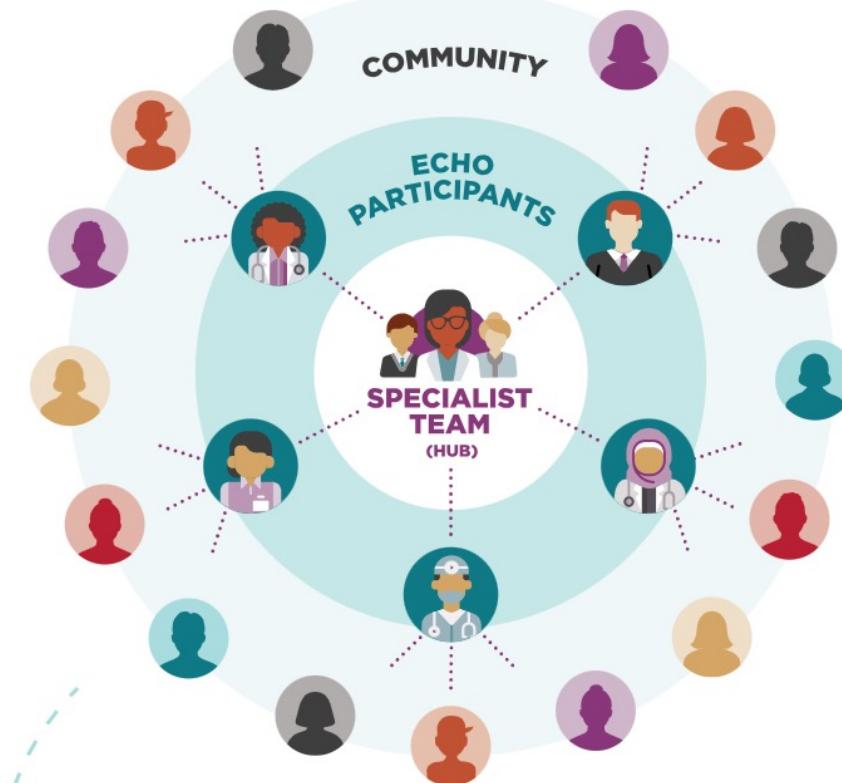


## **“All Teach; All Learn”**

Hub and spoke model of education and mentoring which is -

- Virtual community of peers
- Interactive
- Relies on discussion of real-life cases or problems

## **All Teach, All Learn**



## **Goals**

To share best practices in Amyloidosis care.

To address disparities and challenges in Amyloidosis care delivery

# Connect with ARC Support Services



## Email

[support@arci.org](mailto:support@arci.org)



## Phone

+1 (617) 467-5170



## MAP Tool

[MyAmyloidosisPathfinder.org](http://MyAmyloidosisPathfinder.org)

# Light The Way Forward

[arci.org/givenow](http://arci.org/givenow)



320 Nevada Street, Suite 210 Newton, MA 02460



# Other Ways to Give



- Donor Advised Funds
- Gifts of Stock
- Will or Trust
- Gifts from your IRA
- Workplace Giving
- Fundraisers

**giving@arci.org**  
**arci.org/donate**



Thank You!



# HAPPY HOLIDAYS

*from the Amyloidosis Research Consortium*



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WEBINAR SERIES

## Coffee Chat with ARC

Thank you for joining us today.  
Please take a few minutes to fill  
out the post webinar survey.