

ARC  TALKS
— WEBINAR SERIES

Coffee Chat with ARC

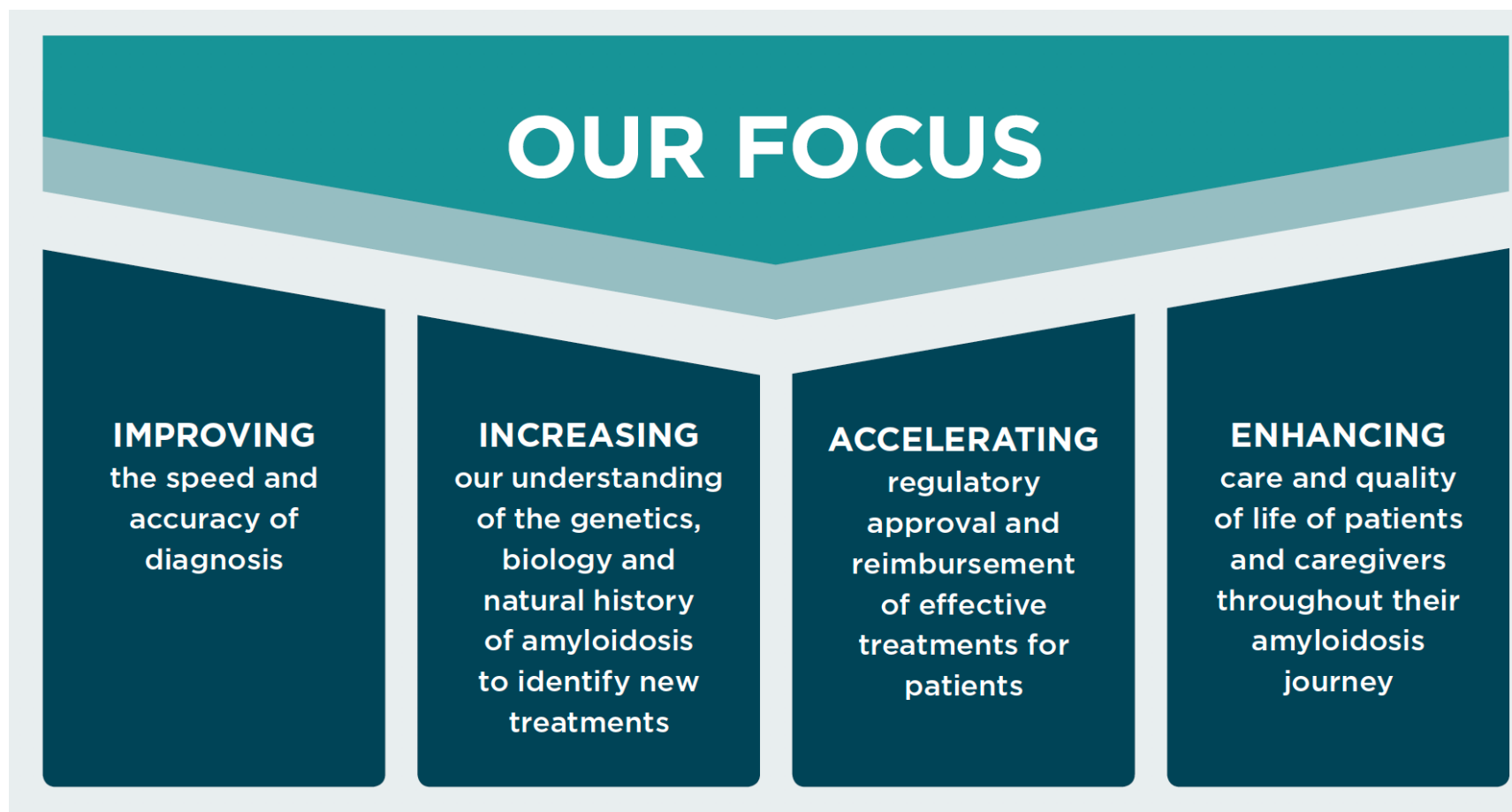
December 18 | 12pm ET



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



ARC Talks Supported By



ALEXION



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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 | 617-467-5170

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.

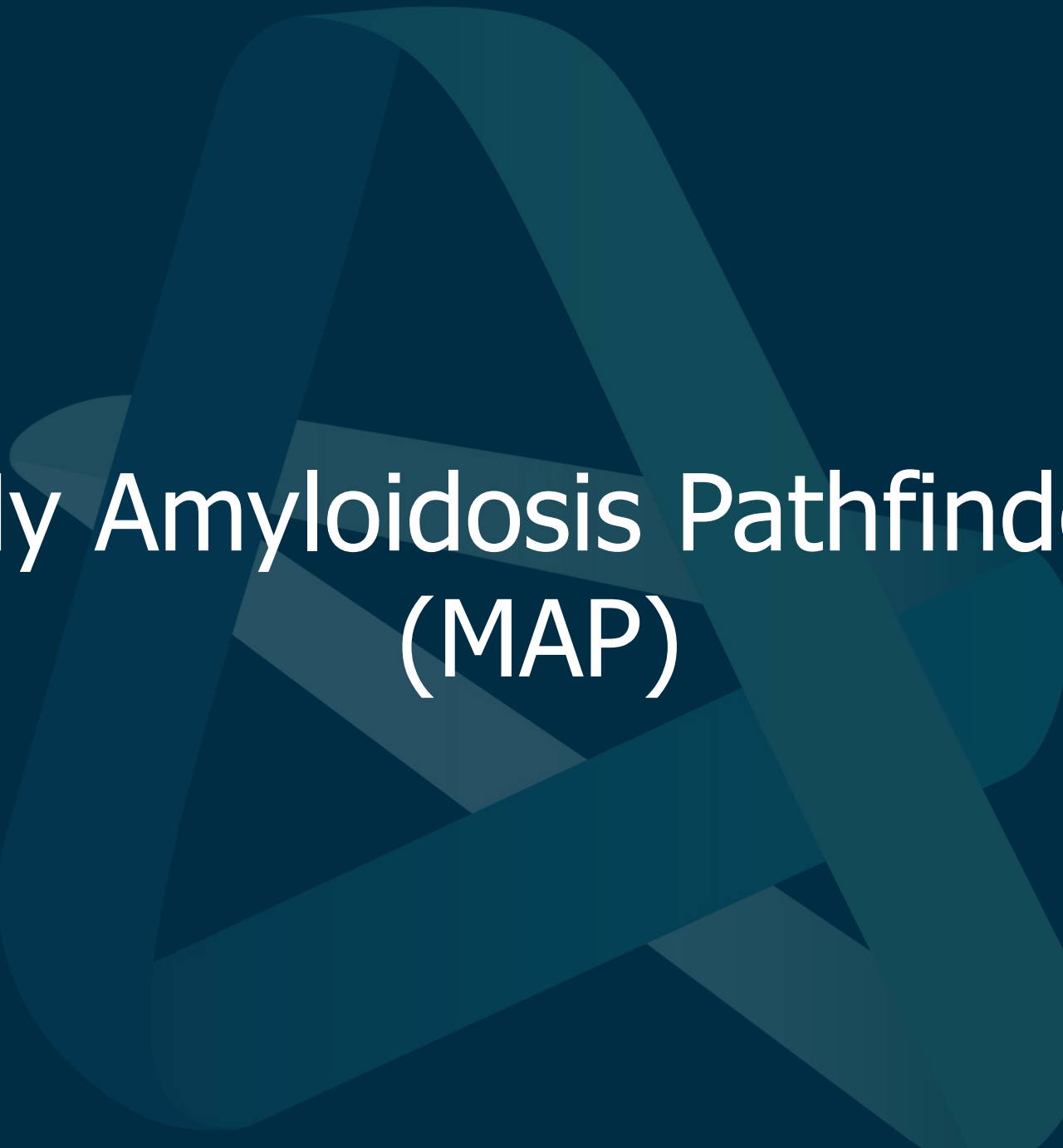
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New to Amyloidosis

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](tel: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



ARC Clinical Fellowship Program

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

IONIS

Alnylam[®]
PHARMACEUTICALS

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PHARMACEUTICAL COMPANIES
OF Johnson & Johnson

novo nordisk[®]

Pfizer

Intellia
THERAPEUTICS

AstraZeneca



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



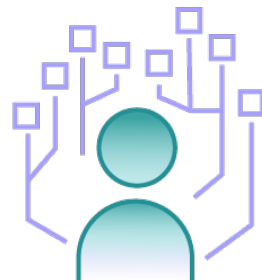
Coordinated Care

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



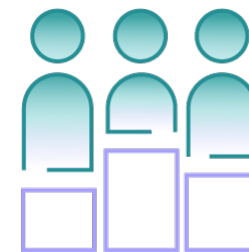
Diagnostic Pathways

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

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, BS (Hons) PhD; MD; Lori Rayner, PhD; Nisha Kumar, MBA; Spencer Guthrie, MBA; Yvonne Narayan, PhD; David Chappin, MD



ASPIRE Rebranding

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



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

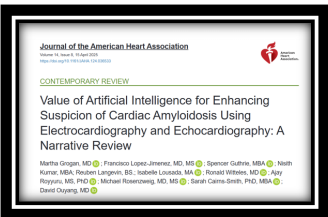
CCCWG showcased a poster at the 2024 Annual Conference of the International Society of Amyloidosis (ISA).

1st Annual Impact Report

First ASPIRE Impact Report published

JAHA 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



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-Nicolau¹, Johana Fajardo^{2,11}, Alyssa Galloway^{3,11}, Sami Khella⁴, Nisith Kumar^{5,11}, Reuben Langevin^{6,11}, Michaela Liedtke⁷, Isabelle Lousada^{6,11}, Tiffany Patrick^{8,11}, Gabriela Tamariz^{9,11}, Karthikeyan Veeraraghavalu^{9,11}, Lori Klein¹⁰, Alexandra Haddad-Angulo^{5,11}

Affiliations: ¹Mayo Clinic, ²Duke University Hospital, ³BridgeBio, ⁴Penn Medicine, ⁵Pfizer Inc., ⁶Amyloidosis Research Consortium (ARC), ⁷Stanford Health Care, ⁸Alnylam Pharmaceuticals, ⁹Prothena Biosciences, ¹⁰Putnam, ¹¹Amyloidosis Stakeholder Partnerships for Impact, Reach & Equity (ASPIRE)

Frequency of Mentions	SAC Core Team Healthcare Providers	Patients	
	 Lack of early/accurate diagnosis	 Delayed / missed diagnosis	Two thirds of patients note having had to see 3 or more physicians before meeting someone who was knowledgeable enough to suspect amyloidosis
	 Lack of access to SACs	 Insufficient education	Many patients note their amyloidosis education at the time of diagnosis was insufficient, and seek out online resources to support self-education
	 Financial burden of treatments to patients	 Insurance hurdles	Over a third of patients note delayed treatment due to insurance issues
	 Telehealth regulations	 Travel burden	Travel to SACs is burdensome due to the financial impact (e.g., travel costs, days off work, caregiver commitment) and the physical consequences (e.g., swelling and pain)
	 Difficulties receiving medical records from HCPs	 Emotional distress	Patients note the desire for resources to support emotional and psychosocial support for both themselves and their caregivers, such as patient support groups
	 Barriers to cross-SAC collaboration		

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



Phone

+1 (617) 467-5170



MAP Tool

MyAmyloidosisPathfinder.org

Support ARC

Light The Way Forward

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



ARC ||||| TALKS

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Please take a few minutes to fill
out the post webinar survey.