

A stylized graphic of a torch with a white handle and a red flame, set against a dark red background with abstract circular shapes.

# AL AMYLOIDOSIS NATIONAL WEBINAR

Follow-Up from the March 12<sup>th</sup>  
National AL Amyloidosis  
Patient-to-Provider Connection Forum

May 14, 2025



# Welcome & Introductions

**Devin Marie Keating**

Director of Operations, Clinical Studies  
American Heart Association

**Cayla Hadley**

Program Implementation Manager  
American Heart Association



# Meeting Reminders

## Please Note:

- This webinar is being recorded.
- All participants will be muted upon entry.
- Recordings of today's sessions will be enduring resources in a few weeks on [www.heart.org](http://www.heart.org)

## Questions?

- We encourage an open, conversational discussion, so please engage and share your thoughts!
- Q&A is scheduled at the end of the webinar.
- Submit your questions in the chat anytime—they will be addressed during the designated Q&A.

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**If you are having issue with audio, please call in using the appropriate number below.**

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# Agenda:

1. Welcome & Opening Remarks
2. Forum Key Findings & What We Learned from The Experts
3. Survey Insights & Innovative Solutions to Challenges
4. AL Amyloidosis Educational Toolkit Launch
5. Q&A



# THANK YOU to Our Forum Speakers & Panelists!



**Linda Perez**

Patient Advocate



**Yevgeniy Brailovsky, DO, MSc**

NewYork-Presbyterian/Columbia  
University Irving Medical Center  
Assistant Professor of Medicine, Cardiology



**John O. Clarke, MD**

Stanford Medicine  
Clinical Professor of Medicine, Division of  
Gastroenterology & Hepatology; Director,  
Esophageal Program; Vice-Chief, Education



**Mazen Hanna, MD**

Cleveland Clinic  
Co-Director, Amyloidosis Center



**Heather J. Landau, MD**

Memorial Sloan Kettering Cancer Center  
Director, Amyloidosis Program;  
Hematologist/Oncologist



**Jai Radhakrishnan, MD, MS**

NewYork-Presbyterian/Columbia University  
Irving Medical Center  
Professor of Medicine, Division of Nephrology



**Julie Rosenthal, MD**

Mayo Clinic Hospital - AZ  
Director, Cardiac Amyloidosis Program;  
Assistant Professor of Medicine, Cardiology



**Brett Sperry, MD**

Saint Luke's Community Hospital  
Associate Professor of Medicine, Cardiology



**Deborah D. Boedicker, CFA**

Mackenzie's Mission &  
Amyloidosis Speakers Bureau  
Board Member



**Muriel Finkel**

Amyloidosis Support Groups  
President & Co-Founder



**Isabelle Lousada**

Amyloidosis Research Consortium  
Founder and CEO



**Naim Essam Bideiwy, FNP-C, MSN**

NewYork-Presbyterian/Columbia University  
Irving Medical Center  
Cardiology

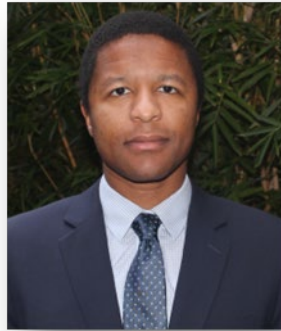


**Tammy Reideler, MSN, RN, OCN**

Mayo Clinic Hospital - FL  
Acute Leukemia and Amyloidosis Nurse  
Navigator



# AL Amyloidosis Expert Collaborative Leadership



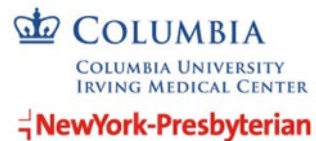
**Kevin M. Alexander, MD**

Assistant Professor of Medicine,  
Advanced Heart Failure and Transplant Cardiology,  
*Stanford Medicine*



**Melissa A. Lyle, MD, FACC, FHFSA**

Assistant Professor of Medicine,  
Division of Advanced Heart Failure and Transplant,  
*Mayo Clinic Florida*



**Mathew Maurer, MD**

Professor of Medicine,  
Arnold and Arlene Goldstein Professor of Cardiology,  
*New York-Presbyterian Hospital-Columbia University Medical Center*





# Forum Key Findings & What We Learned from The Experts

**Melissa Lyle, MD, FACC, FHFSA**

*Assistant Professor of Medicine*

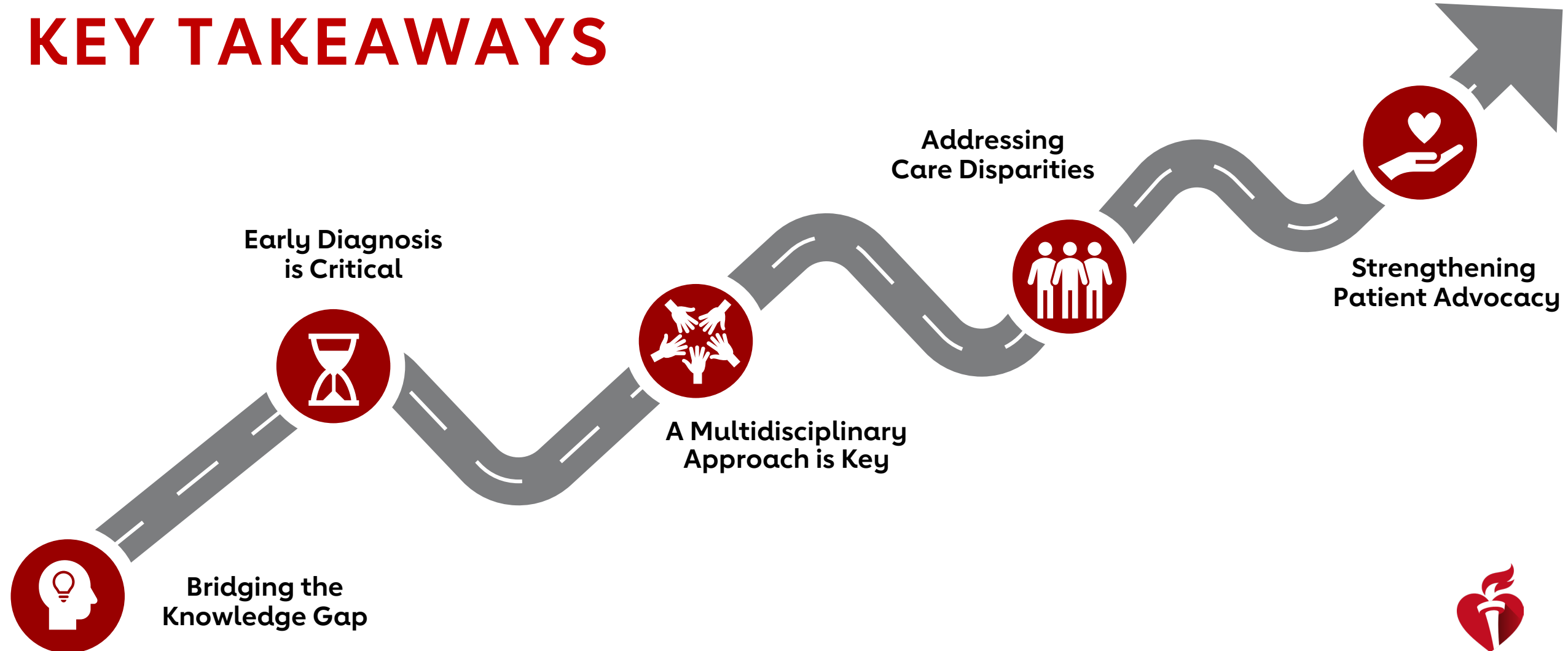
*Division of Advanced Heart Failure and Transplantation*

Mayo Clinic Florida



# National AL Amyloidosis Patient-to-Provider Connection Forum:

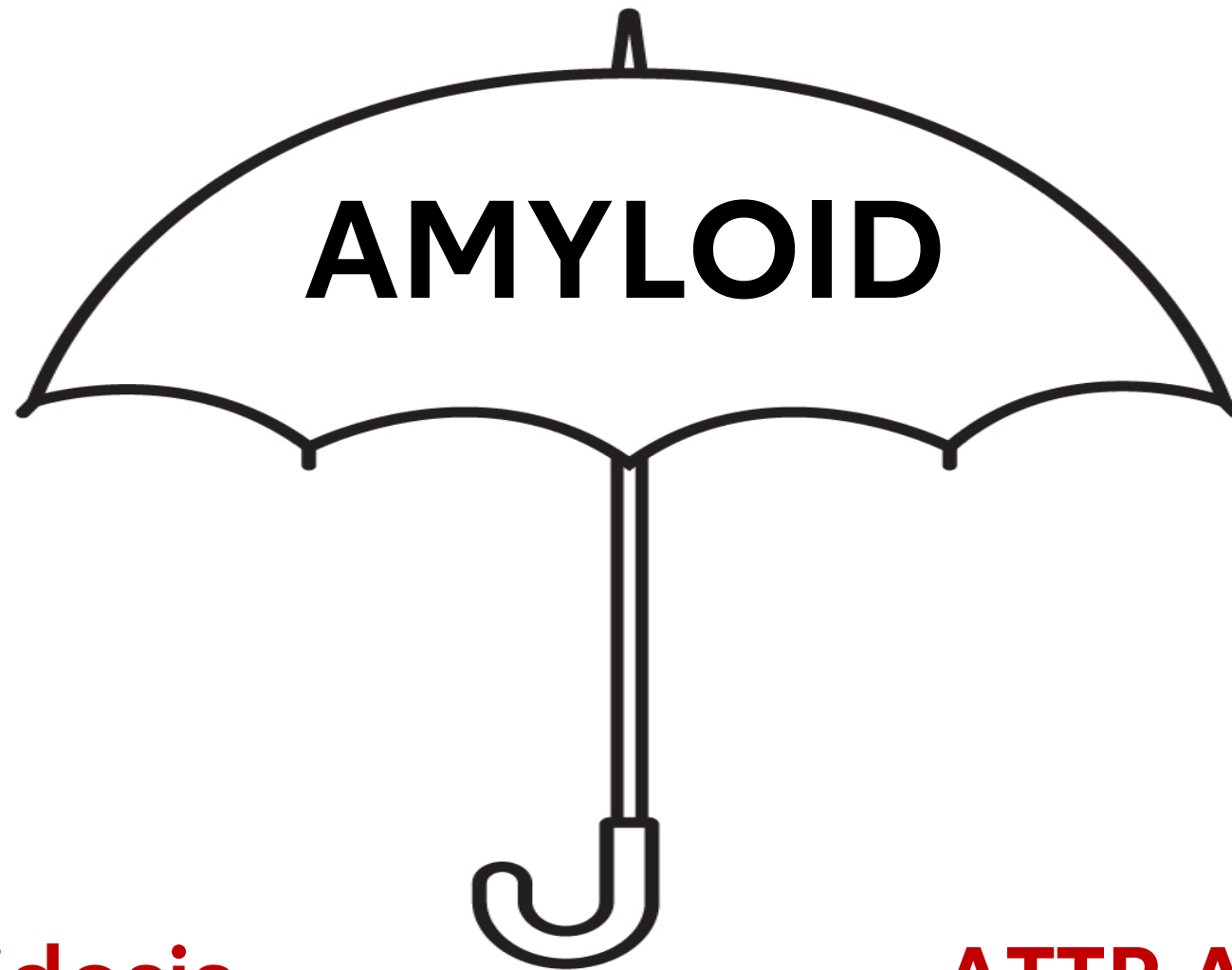
## KEY TAKEAWAYS





# AL Amyloidosis Disease Overview





## **AL Amyloidosis**

**Protein:** Immunoglobulin light chain

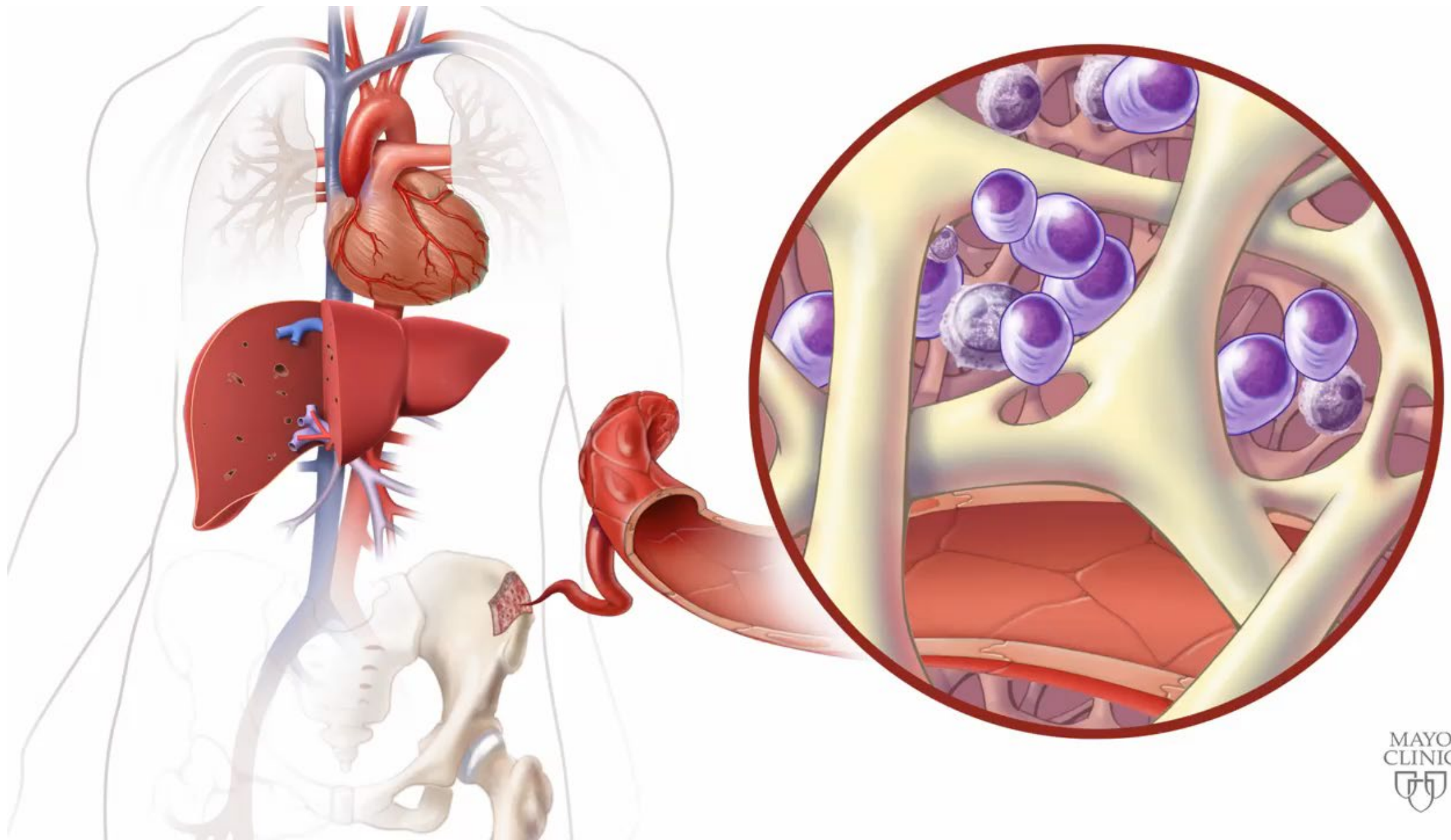
**Protein Factory:** Plasma Cells in bone marrow

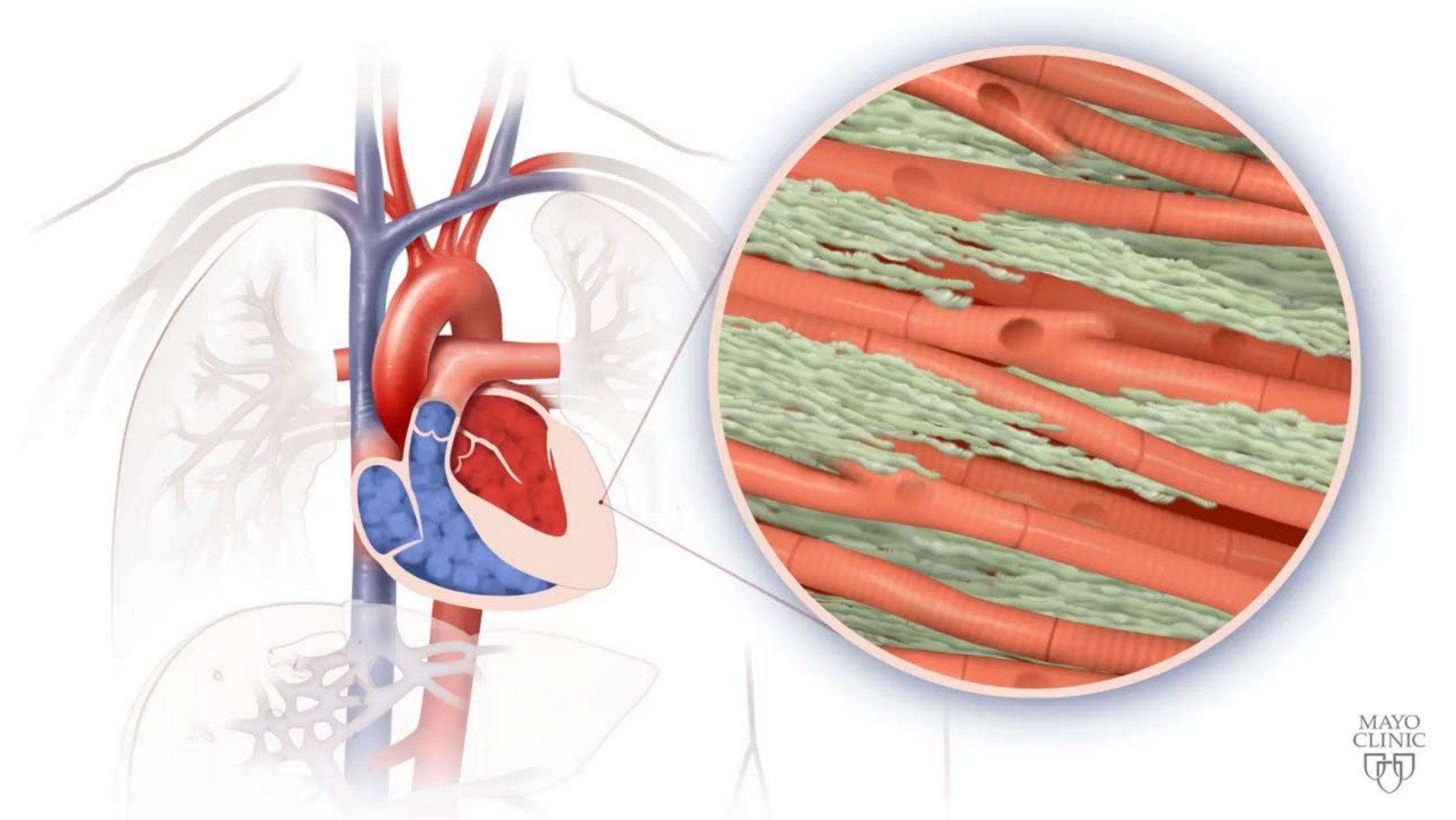
## **ATTR Amyloidosis**

**Protein:** Transthyretin (TTR)

**Protein Factory:** Liver







## AL (light chain)



Multi-organ involvement, **heart failure**, hepatomegaly, nephrotic syndrome, peripheral and autonomic neuropathy, macroglossia, periorbital purpura, carpal tunnel

## Variant ATTR



Heart failure +/- peripheral neuropathy

- V122I (3-4% US Black population)
- T60A
- V30M

## Wild type ATTR



**Heart failure**, bilateral carpal tunnel, biceps tendon rupture, spinal stenosis, atrial fibrillation



# Prevalence

- Estimated annual incidence 1 in 75,000–100,000
- Prevalence 1 in 25,000
- 75% cardiac involvement
- 1 in 7 patients with multiple myeloma have concomitant AL amyloidosis

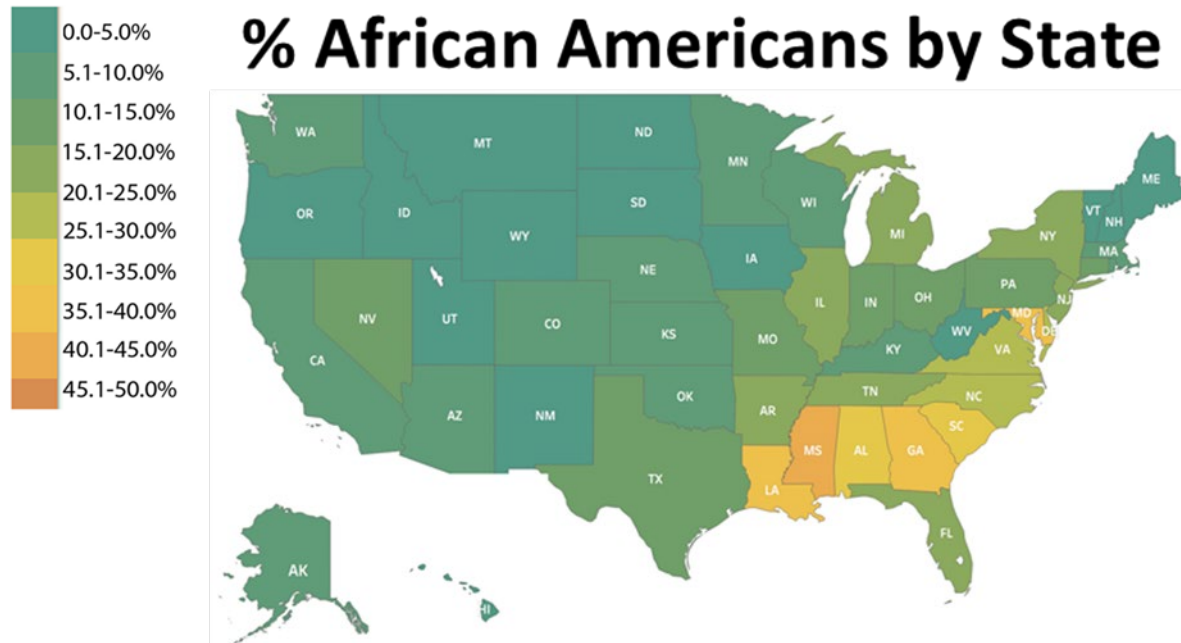




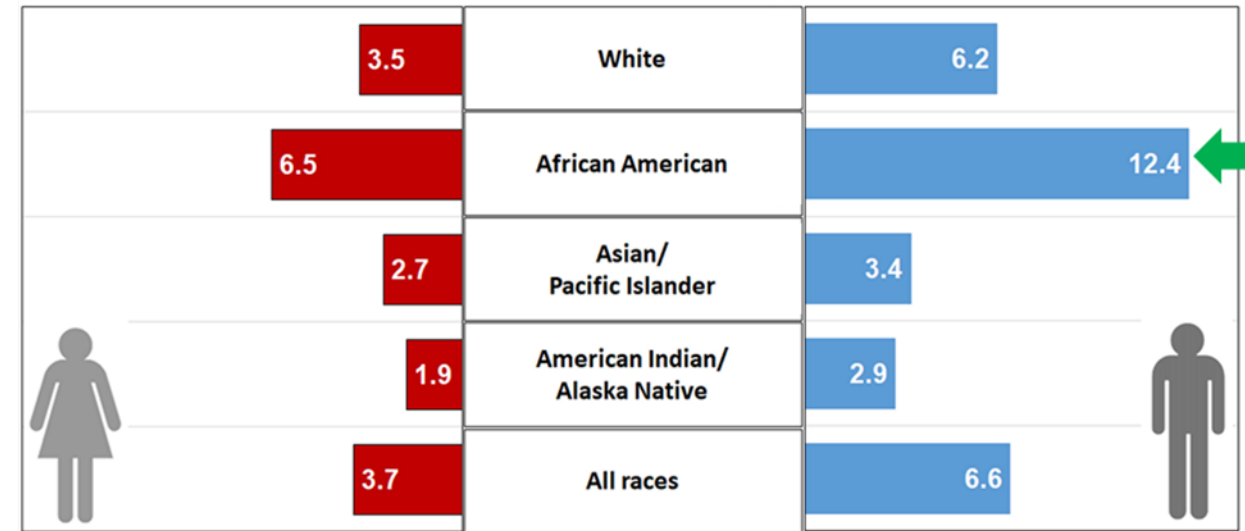
# Addressing Care Disparities



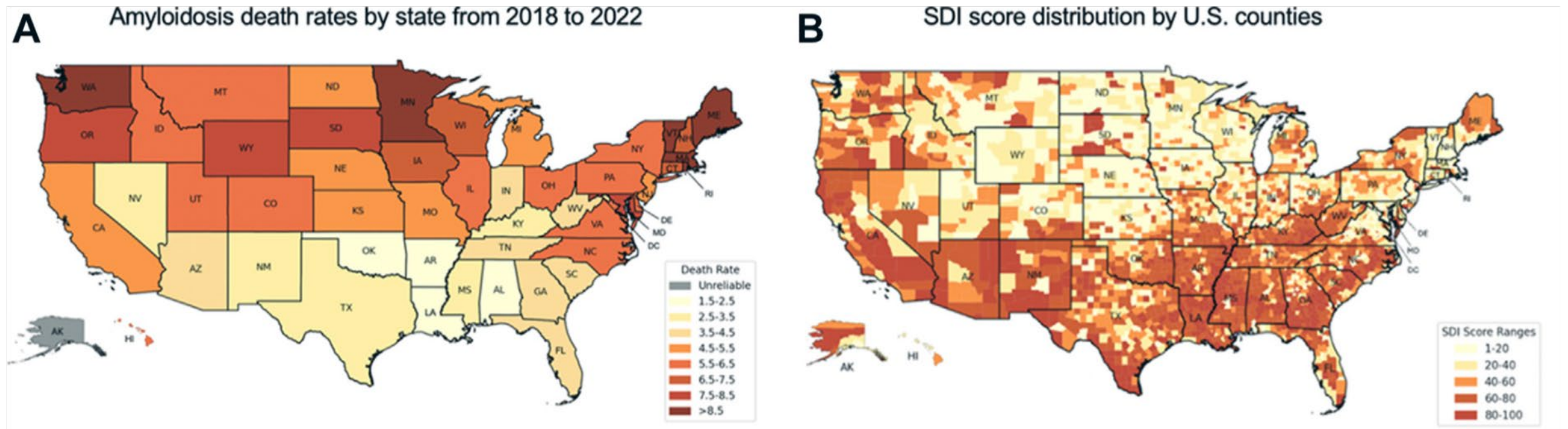
# Disproportionate Impact and Underdiagnosis in Black Individuals



Age-adjusted amyloidosis mortality rate per 1,000,000



# Cardiac Amyloidosis Is Disproportionately Underdiagnosed in Socially Vulnerable Areas





# Early Diagnosis is Critical



# Diagnostic Approach

1. Left ventricular wall thickness  $\geq 12$  mm



2.  $\geq 1$  Clinical Clues



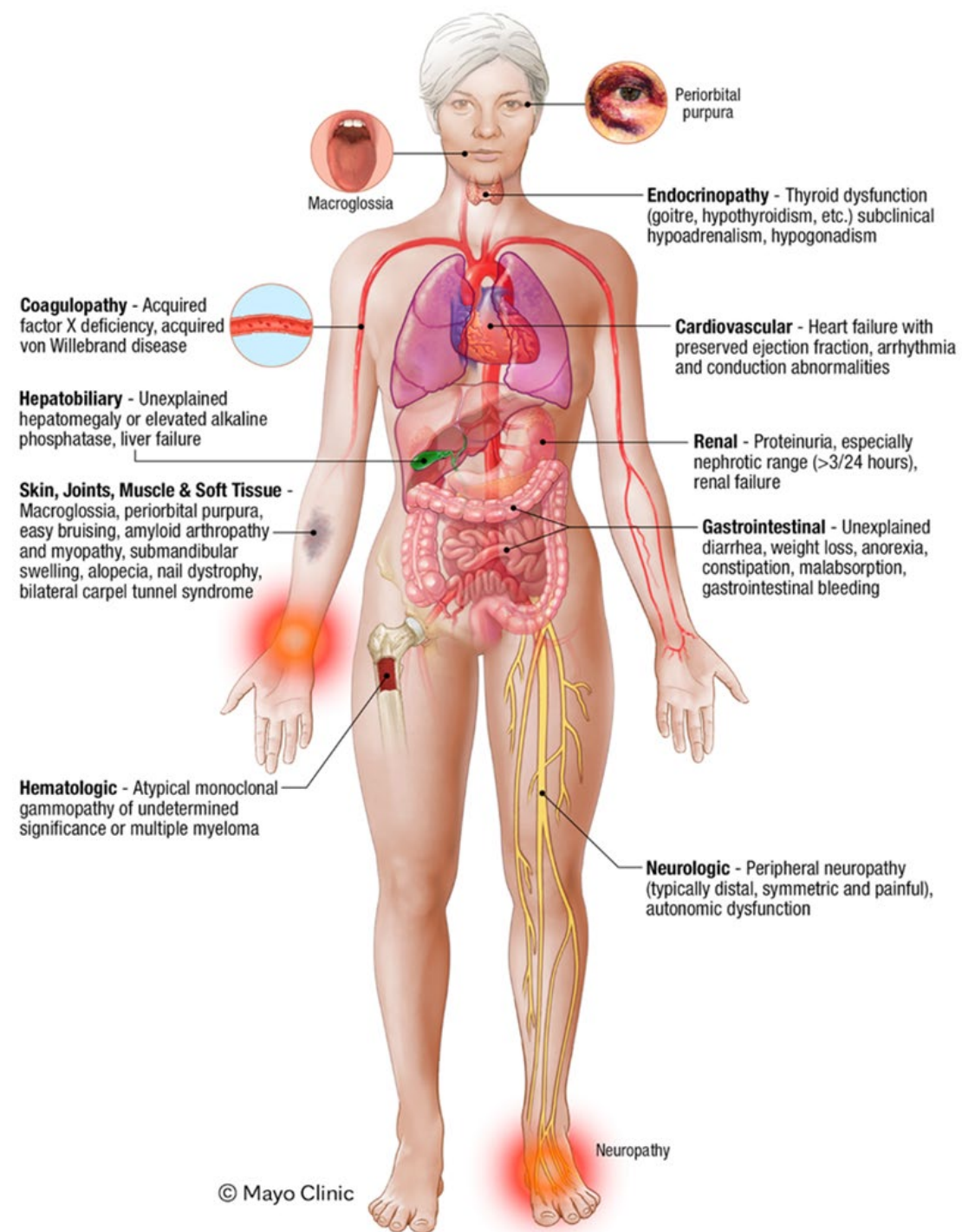


# Clinical Clues

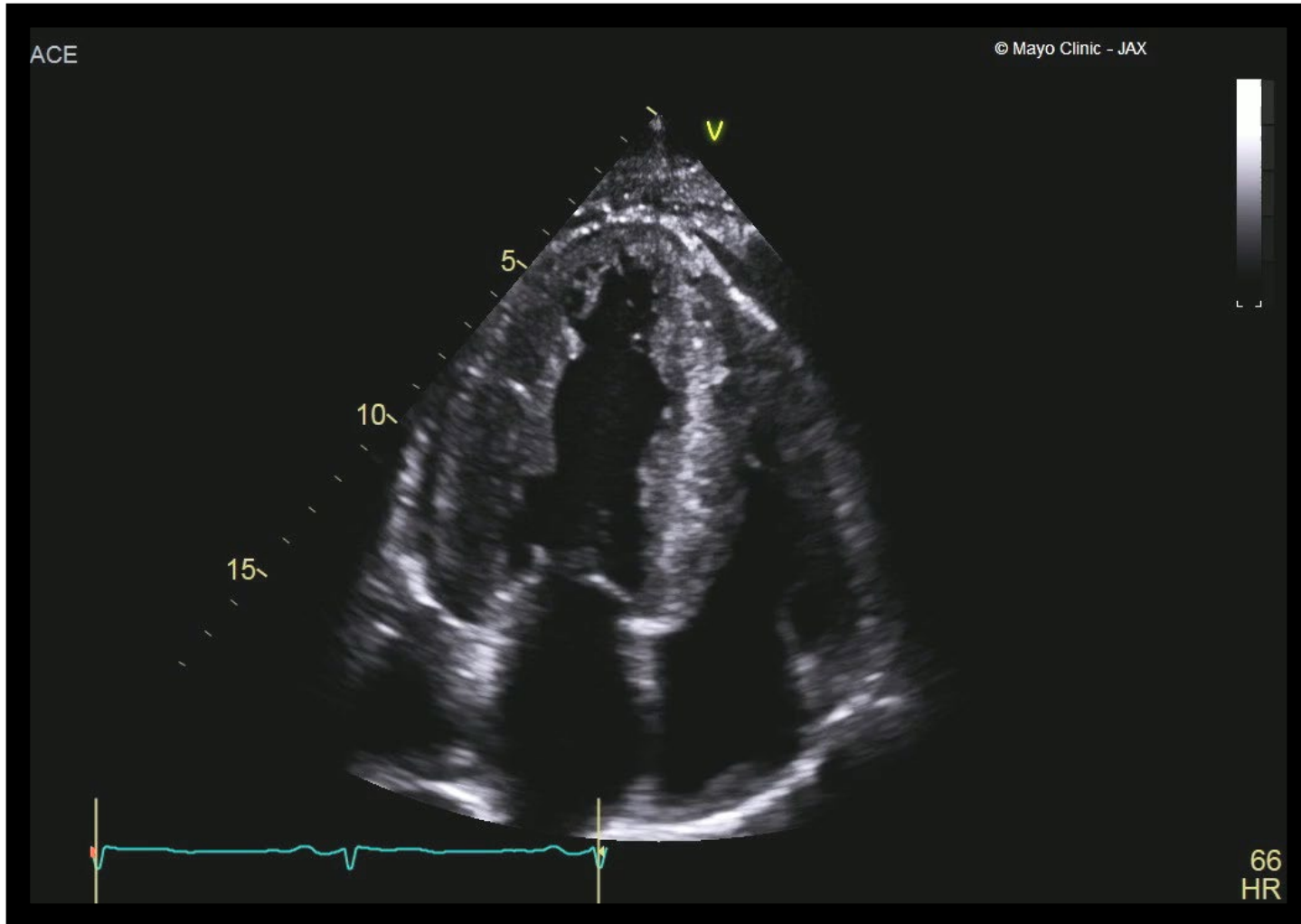


- Heart failure  $\geq$  65 years
- Aortic stenosis in  $\geq$  65 years
- Autonomic dysfunction
- Peripheral polyneuropathy
- Bilateral carpal tunnel syndrome
- Ruptured biceps tendon
- Perioral/periorbital purpura
- Macroglossia
- Low voltage on ECG
- Decreased QRS voltage to mass ratio
- Pseudo Q waves on ECG
- Atrial Fibrillation
- Persistent elevation of cardiac biomarkers
- Intolerance to typical guideline directed medical therapy for heart failure





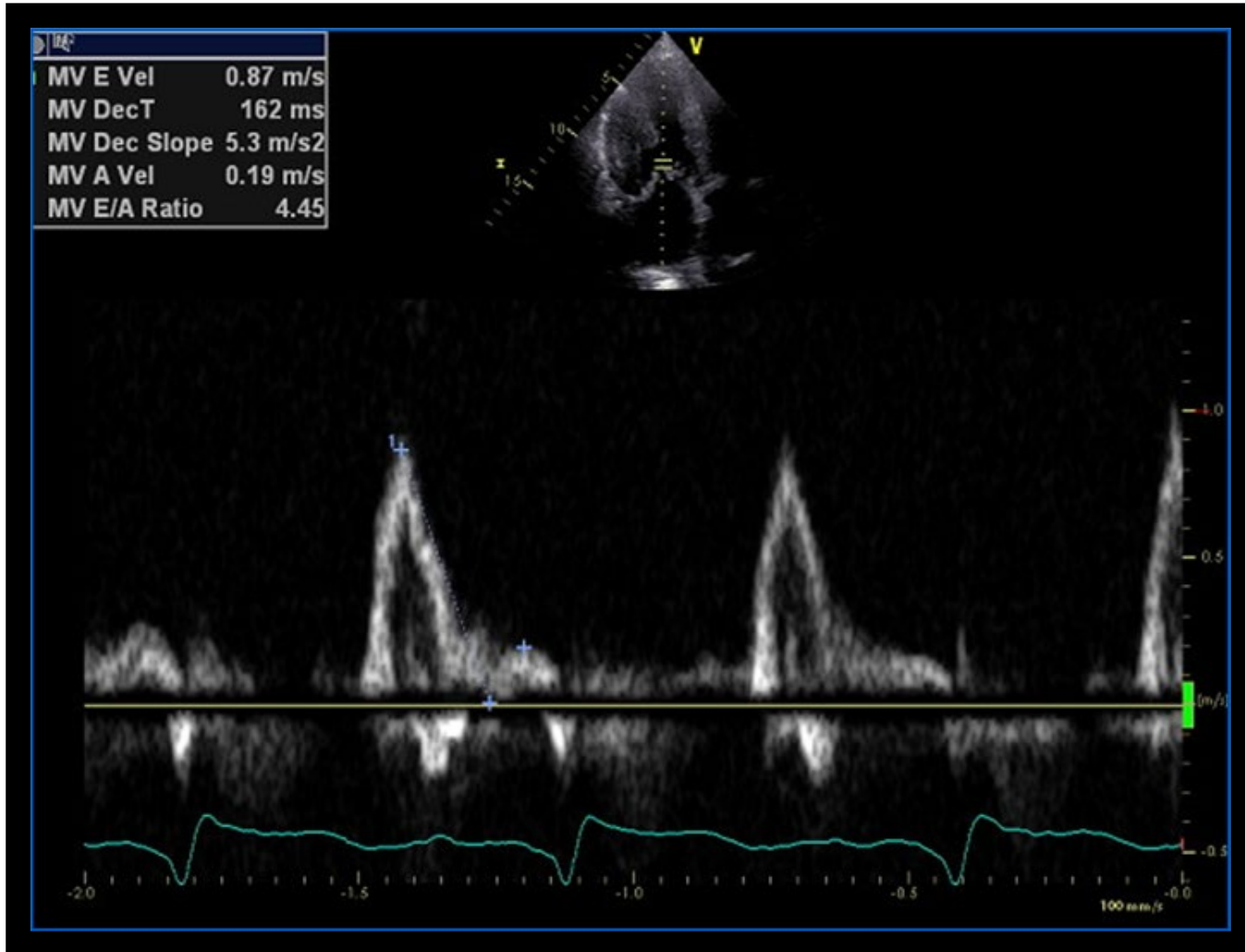
# Echocardiographic Features



- Concentric biventricular wall thickness
- Bi-atrial enlargement
- Thickened valve leaflets and interatrial septum
- Pericardial effusion

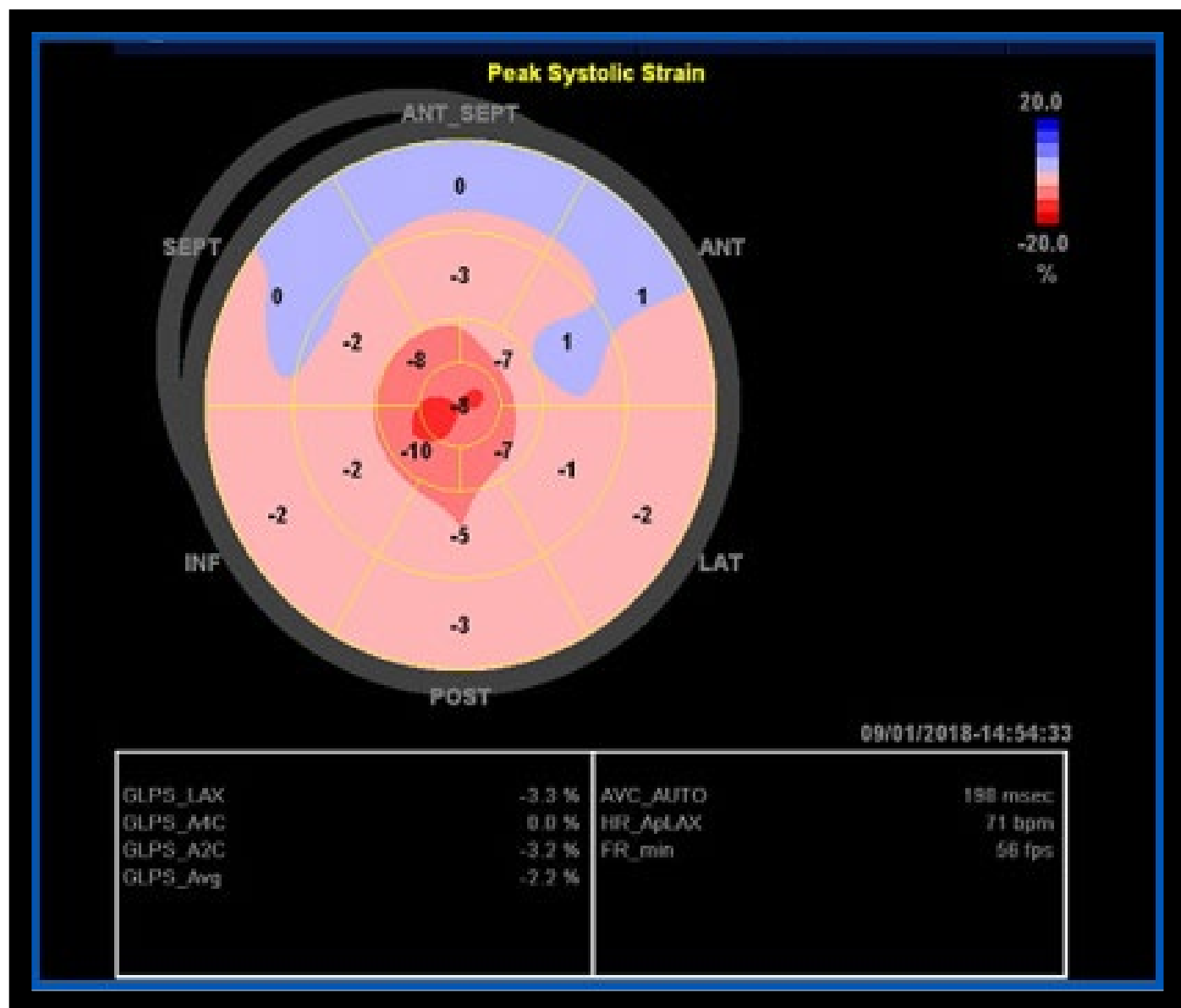


# Echocardiographic Features



- E/A ratio  $> 1.5$
- Deceleration time  $< 150$  ms
- Reduced A wave velocity
- 5-5-5 sign
  - All tissue Doppler velocities  $< 5$  cm/sec





ORIGINAL ARTICLE

**Relative apical sparing of longitudinal strain using two-dimensional speckle-tracking echocardiography is both sensitive and specific for the diagnosis of cardiac amyloidosis**

Dermot Phelan, Patrick Collier, Paaladinesh Thavendiranathan, Zoran B Popović, Mazen Hanna, Juan Carlos Plana, Thomas H Marwick, James D Thomas



# Echocardiographic Prognosis

- Independent echo predictors of mortality
  - $SVI < 33 \text{ mL/min}$
  - Cardiac index
  - LV strain -14%

## ORIGINAL ARTICLE

### **Independent Prognostic Value of Stroke Volume Index in Patients With Immunoglobulin Light Chain Amyloidosis**

See editorial by Siddiqi et al

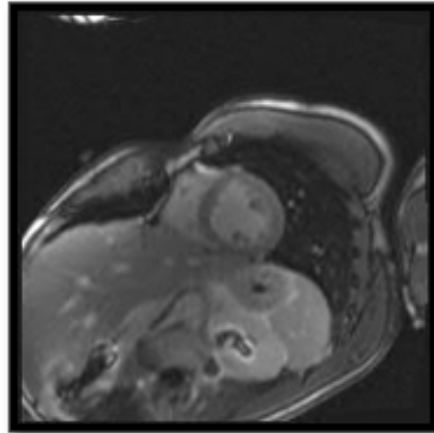
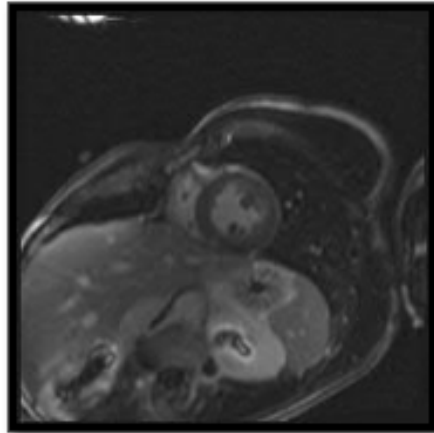
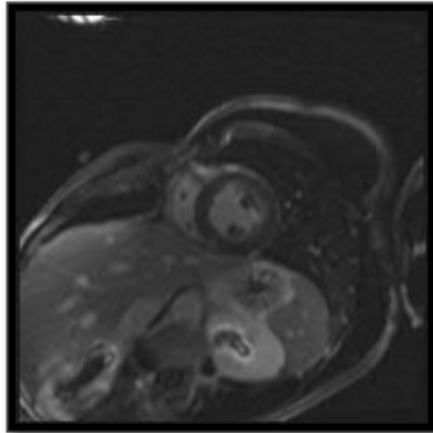
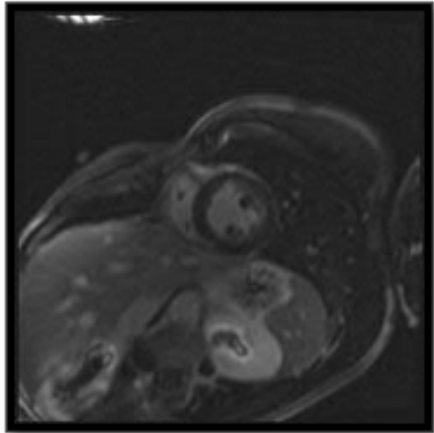
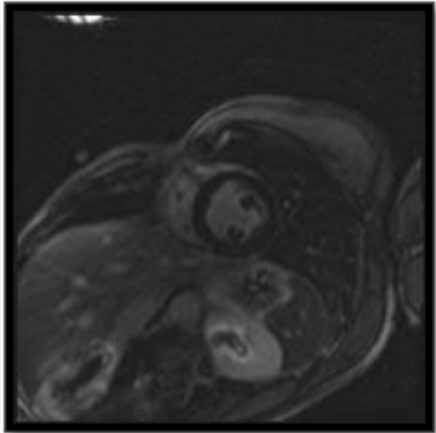
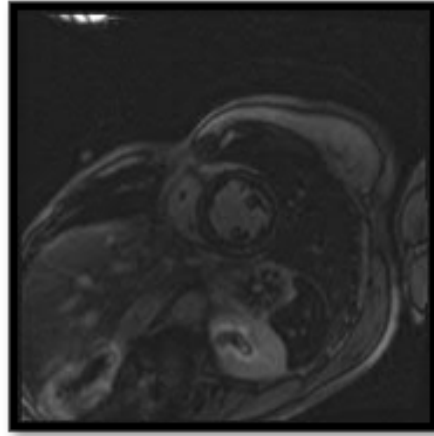
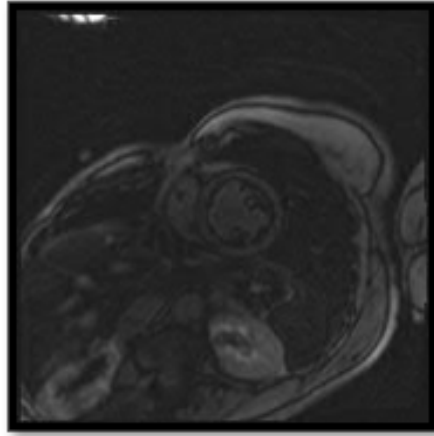
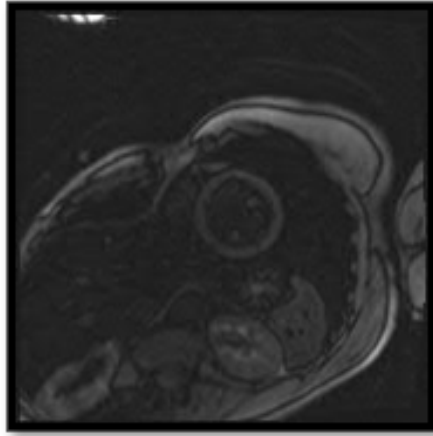
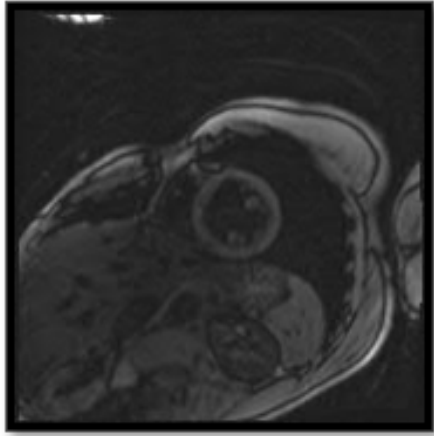
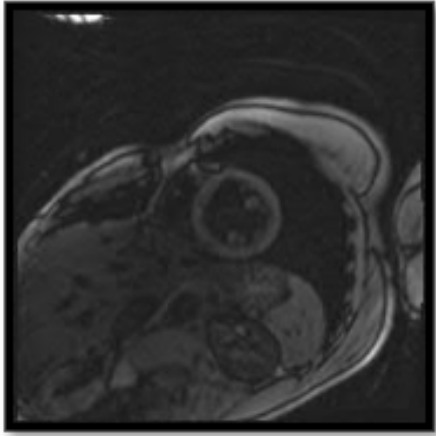
Paolo Milani, MD, Angela Dispenzieri, MD, Christopher G. Scott, MS, Morie A. Gertz, MD, Stefano Perlini, MD, PhD, Roberta Mussinelli, MD, Martha Q. Lacy, MD, Francis K. Buadi, MD, Shaji Kumar, MD, Mathew S. Maurer, MD, Giampaolo Merlini, MD, Suzanne R. Hayman, MD, Nelson Leung, MD, David Dingli, MD, PhD, Kyle W. Klarich, MD, John A. Lust, MD, PhD, Yi Lin, MD, PhD, Prashant Kapoor, MD, Ronald S. Go, MD, Patricia A. Pellikka, MD, Yi L. Hwa, CNP, Stephen R. Zeldenrust, MD, PhD, Robert A. Kyle, MD, S. Vincent Rajkumar, MD, and Martha Grogan, MD



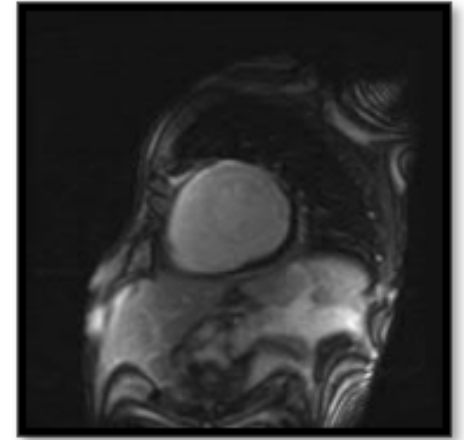
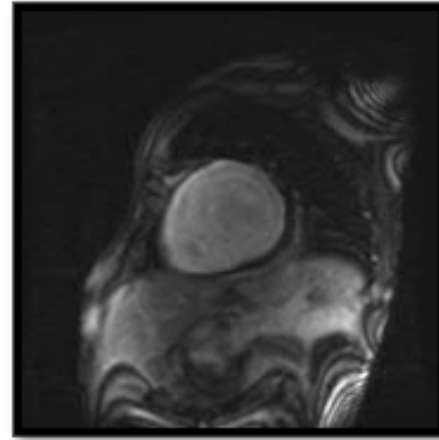
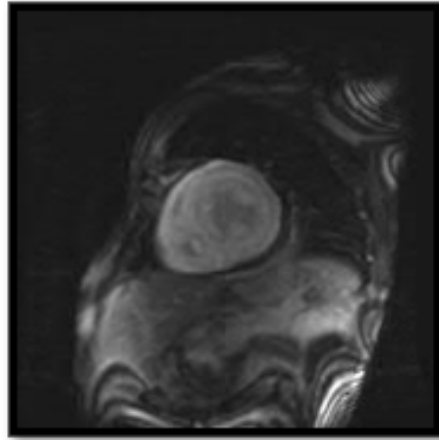
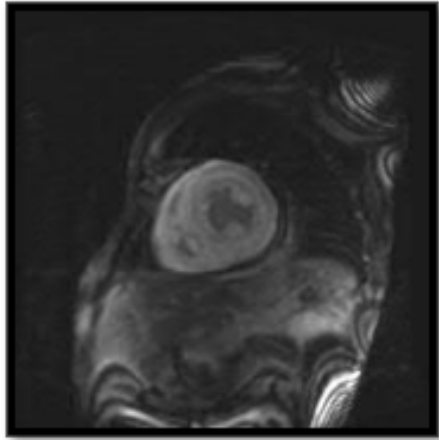
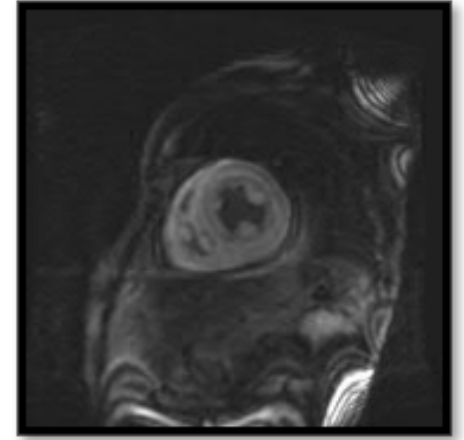
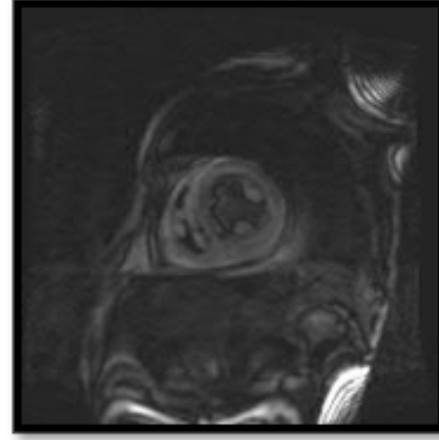
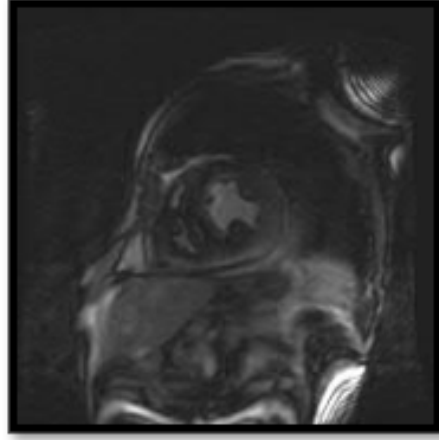
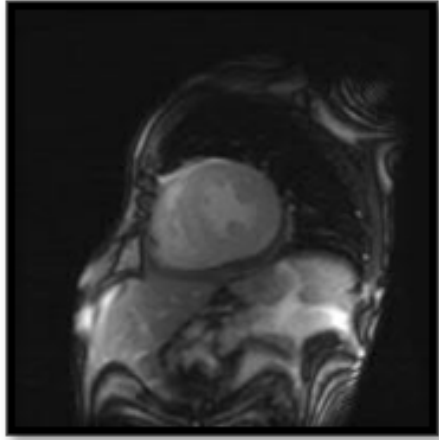
# Cardiac Magnetic Resonance



# Normal Nulling Pattern



# Abnormal Nulling Pattern



# WHAT TO DO NEXT?



# Blood Tests to Screen for Amyloid?

1. CBC with differential
2. Prealbumin
3. Serum free light chains
4. Beta-2 microglobulin



# Diagnostic Algorithm

Clinical suspicion + Echo/MRI Findings

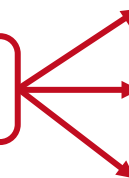


Monoclonal Protein Screen

Serum free light chains

Serum immunofixation  
not SPEP alone

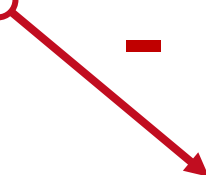
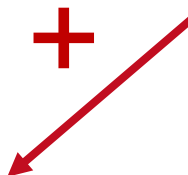
24-hour urine  
immunofixation  
not UPEP alone



Monoclonal Protein?

+

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- Hematology consult
- Biopsy
  - Fat pad biopsy
  - Bone marrow biopsy
  - EMB

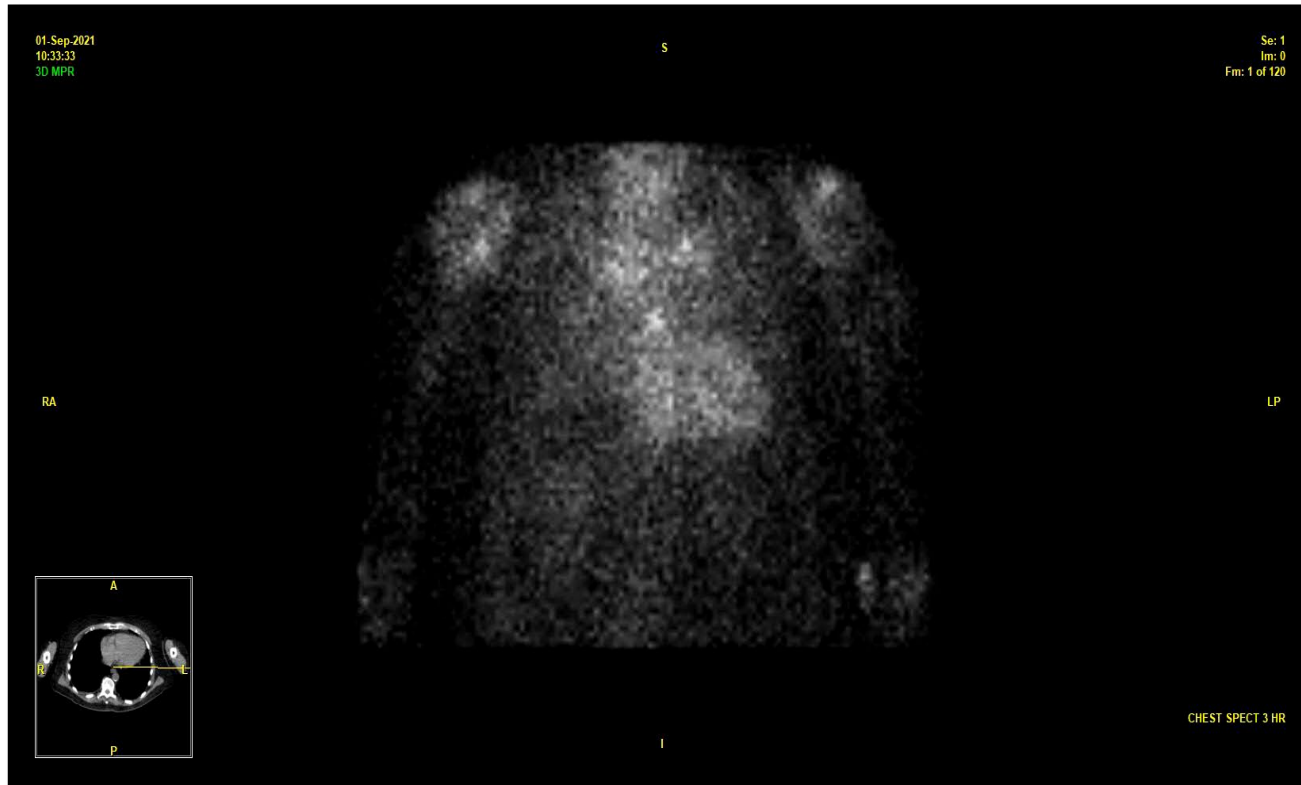
Cardiac scintigraphy



Genetic testing



# Cardiac Scintigraphy



- $^{99m}\text{Tc}$ -labeled pyrophosphate (PYP)
- $^{99m}\text{Tc}$ -labeled 3,3-diphosphono-1,2-propanodicarboxylic acid (DPD)
- $^{99m}\text{Tc}$ -labeled hydroxymethylene diphosphonate (HMDP)



**20% of biopsy proven AL patients had  
Grade 2-3 uptake**

Martha Grogan, MD; Helen J. Lachmann, MD; Sabahat Bokhari, MD; Adam Castano, MD;  
Sharmila Dorbala, MD, MPH; Geoff B. Johnson, MD, PhD;

**Monoclonal gammopathy must be excluded  
to use cardiac scintigraphy**

**Table 4** Possible false positives and false negatives of bisphosphonate scintigraphy for detecting transthyretin cardiac amyloidosis

	Situation	How to suspect and confirm?
<b>False positive</b>	AL amyloidosis	Abnormal SPIE, UPIE or serum free light ratio. Requires histologic confirmation.
	Hydroxychloroquine cardiac toxicity	Interrogation. Requires histologic confirmation.
	AApoAI and AApoAII amyloidosis	Concomitant kidney disease present. Genetic testing.
	ApoAIV amyloidosis	Concomitant kidney disease present. Requires histologic confirmation.
	A $\beta$ 2M amyloidosis	Long-term dialysis (>9 years). Requires histologic confirmation.
	Blood pool	Cardiac dysfunction could be present. Use SPECT to detect uptake in myocardium. Delay acquisition.
<b>False negative</b>	Rib fractures, valvular/annular calcifications	Use SPECT to detect uptake in myocardium.
	Recent myocardial infarction (<4 weeks)	Interrogation. Use SPECT to detect diffuse uptake in myocardium.
	Phe84Leu ATTRv, Ser97Tyr ATTRv	Concomitant neuropathy. Familial disease. Genetic testing.
	Very mild disease	Requires histologic confirmation.
	Delayed acquisition	Shorter acquisition time interval.
	Premature acquisition	Prolong acquisition time interval.

AApoAI, apolipoprotein AI amyloidosis; AApoAII, apolipoprotein AII amyloidosis; AApoAIV, apolipoprotein A-IV amyloidosis; A $\beta$ 2M,  $\beta$ 2-microglobulin amyloidosis; AL, light-chain amyloidosis; ATTRv, hereditary transthyretin amyloidosis; SPECT, single photon emission computed tomography; SPIE, serum protein electrophoresis with immunofixation; UPIE, urine protein electrophoresis with immunofixation.

# Diagnostic Algorithm

Clinical suspicion + Echo/MRI Findings

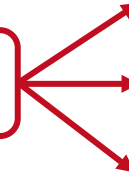


Monoclonal Protein Screen

Serum free light chains

Serum immunofixation  
not SPEP alone

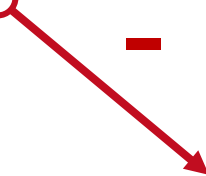
24-hour urine  
immunofixation  
not UPEP alone



Monoclonal Protein?

+

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- Hematology consult
- Biopsy
  - Fat pad biopsy
  - Bone marrow biopsy
  - EMB

Cardiac scintigraphy



Genetic testing

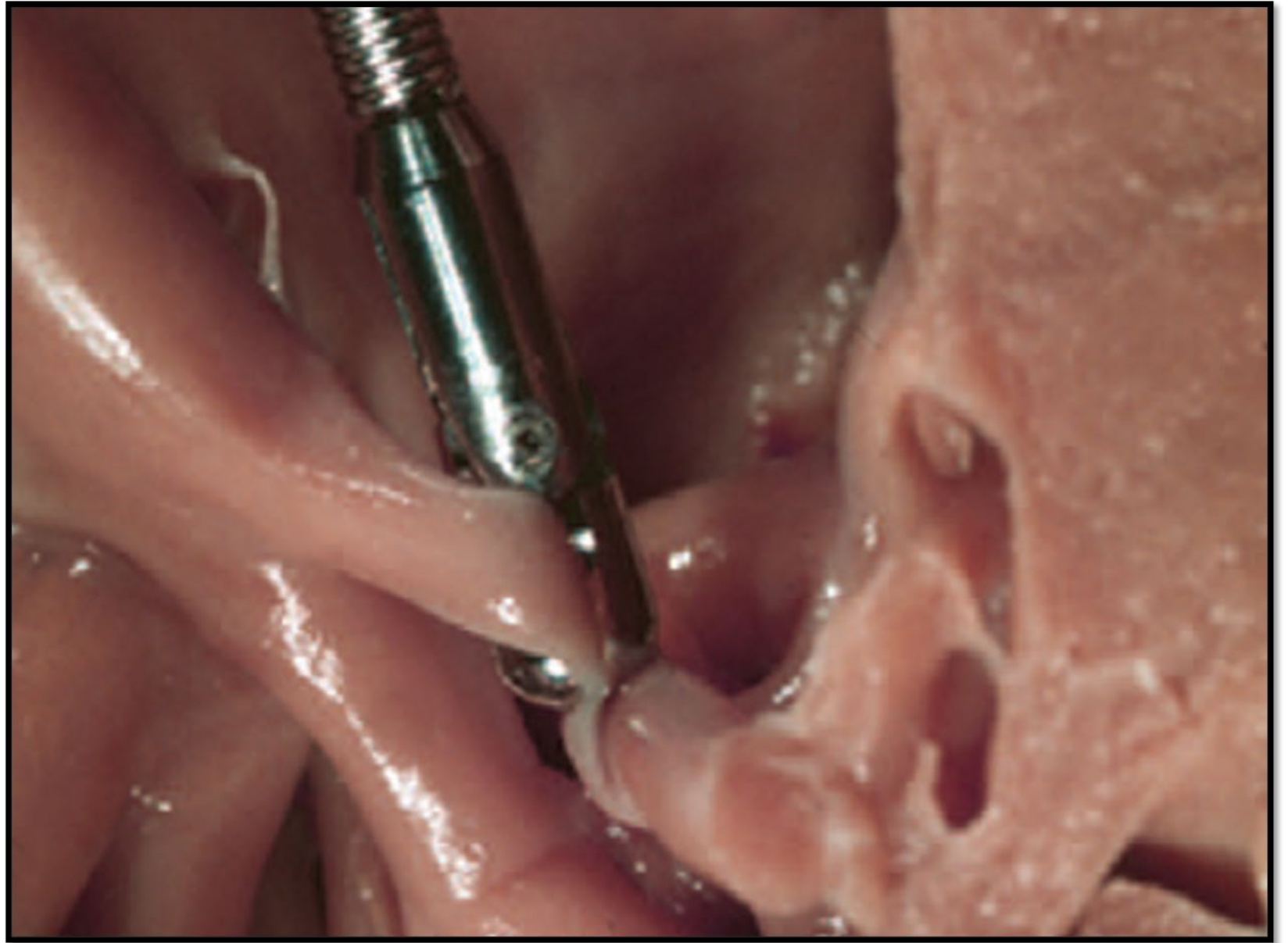


**M** — Must

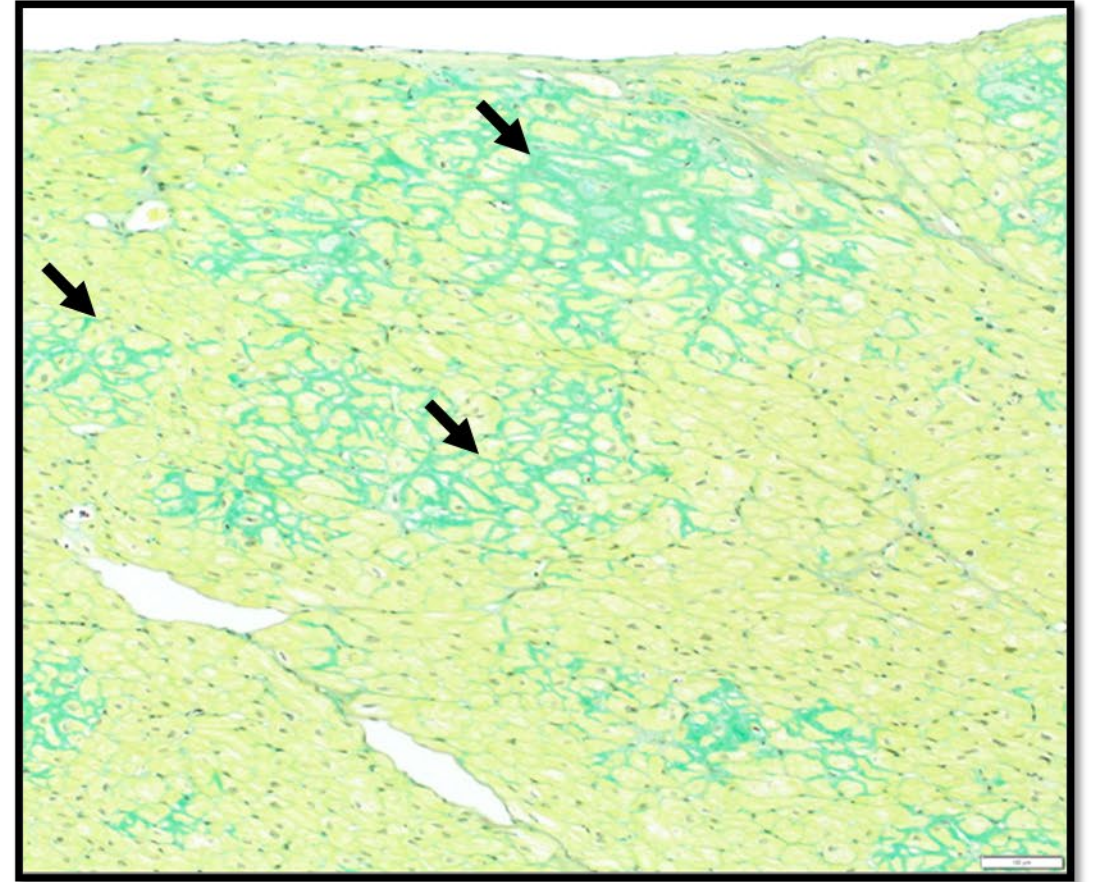
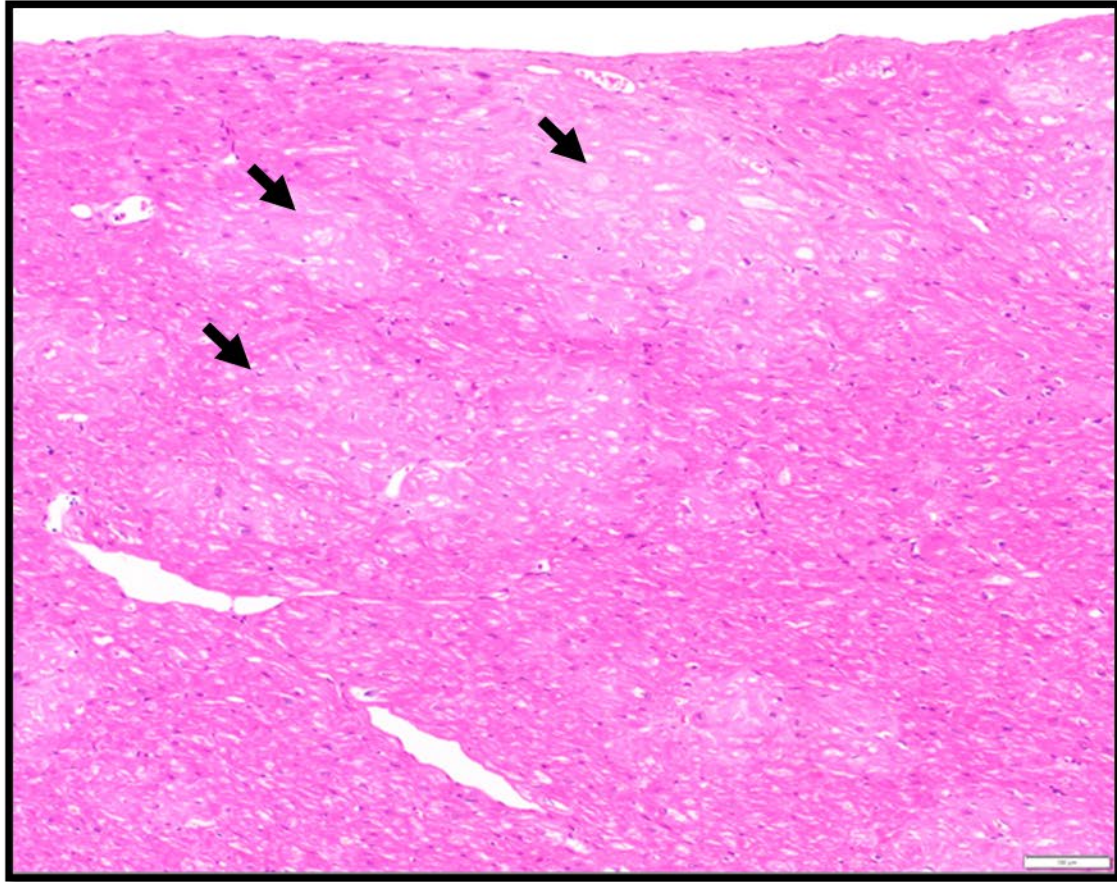
**G** — Go

**U** — Under

**S** — Skin

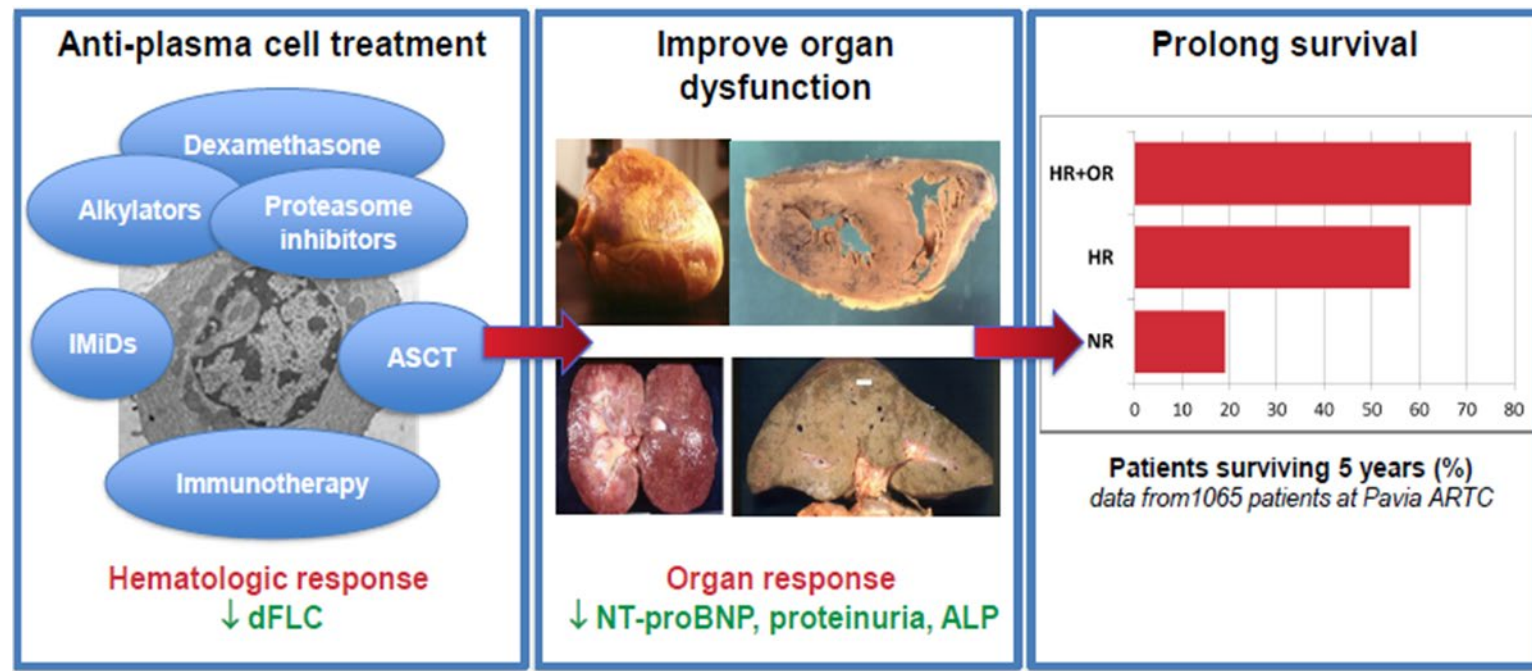


Acronym courtesy of Dr. Dan Judge, shared by Dr. Martha Grogan, Mayo Clinic Rochester



# Goal of Treatment in AL Amyloidosis

Target the diseased plasma cell clone to improve organ function and prolong survival



FLCs= monoclonal free light chains

HR= hematologic response

OR= organ response

NR= no response

CR= complete response

NT-ProBNP= N-terminal pro-B-type natriuretic peptide

ALP= alkaline phosphatase

**Deeper Hematologic Response**

**↑ Organ Response**

**HR + OR = Longer Survival**

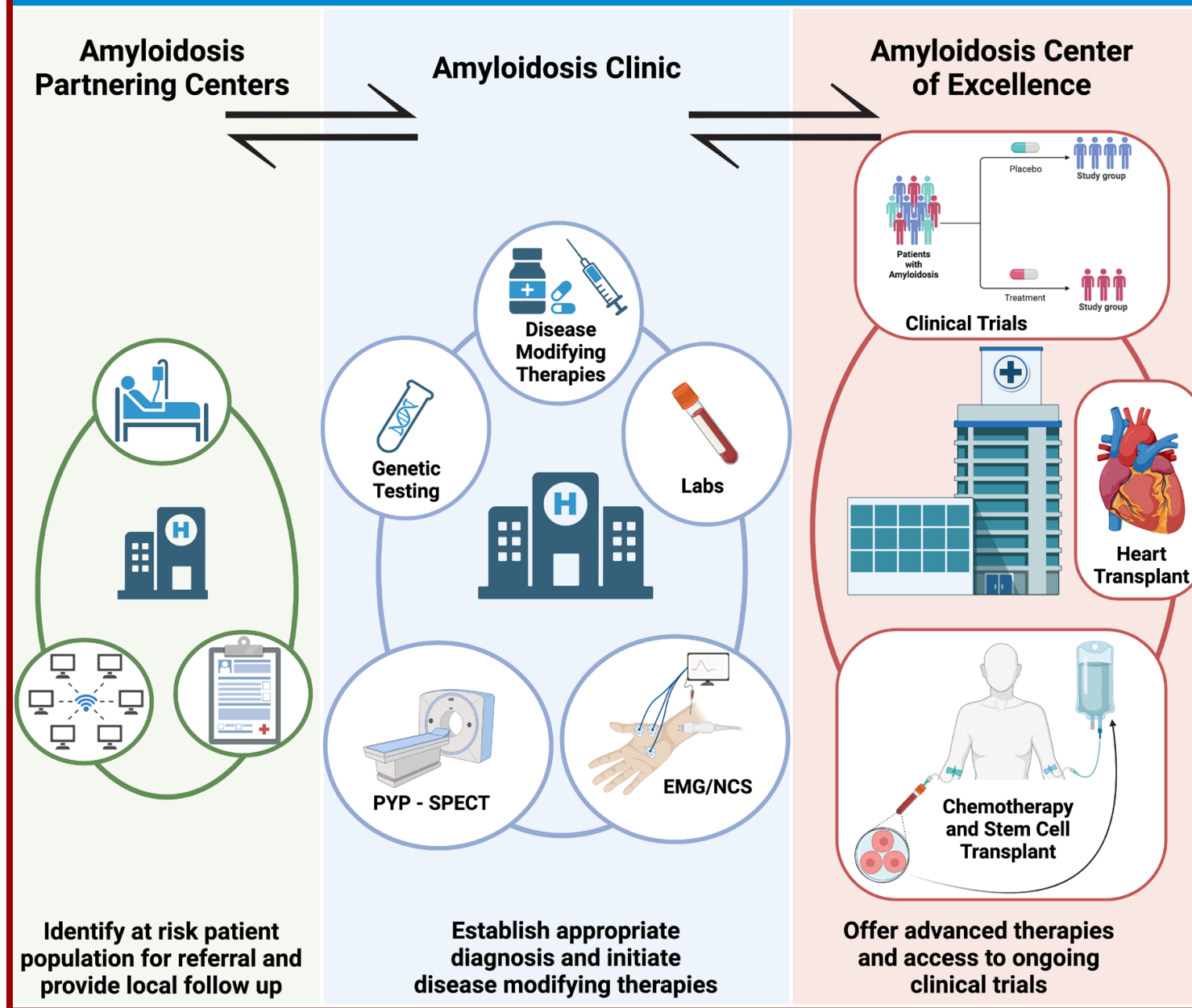




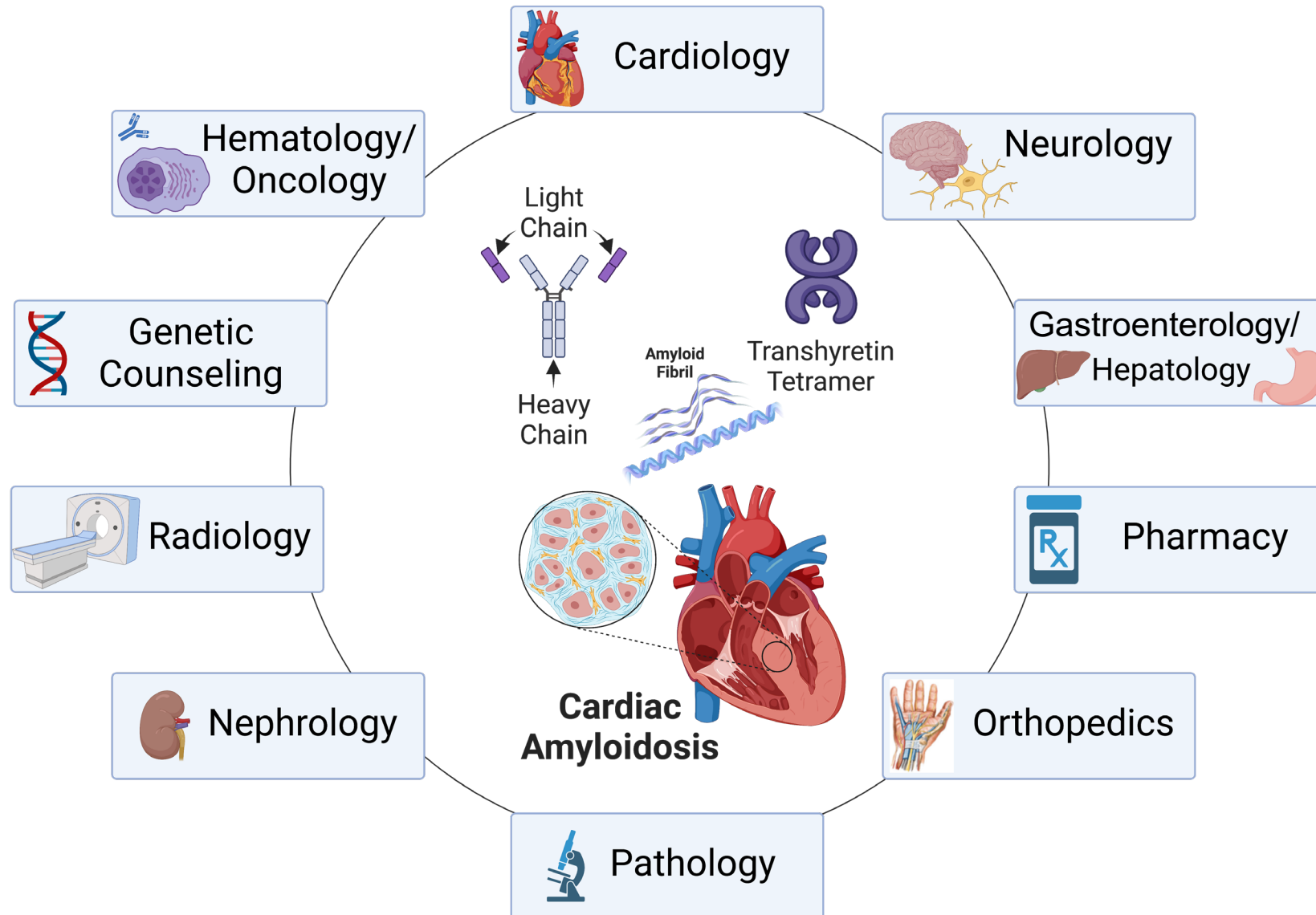
# A Multidisciplinary Approach is Key



**Figure.** Multilevel Collaboration Between Centers Caring For Patients With Amyloidosis.



# Team will Vary by Institution





# Bridging the Knowledge Gap



# CHALLENGES

**Delayed Diagnosis**

**EDUCATION +  
SCREENING TOOLS**

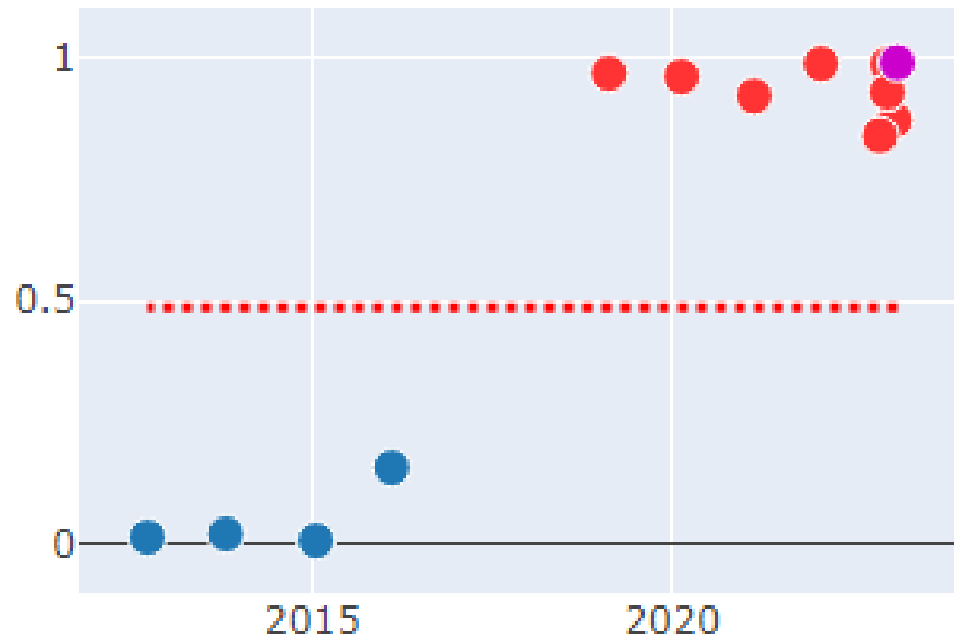
**Complex Diagnosis**

**Multi-Organ  
Involvement &  
Complex Therapies**



# Artificial Intelligence

Probability of Amyloid



 AI Dashboard

[Show images for ECG 12 Lead](#)



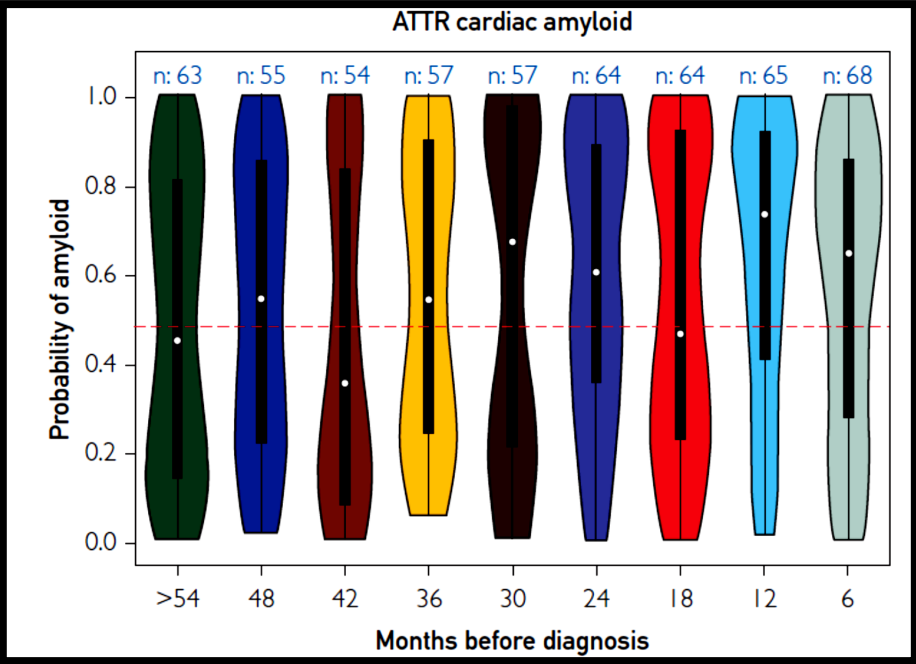
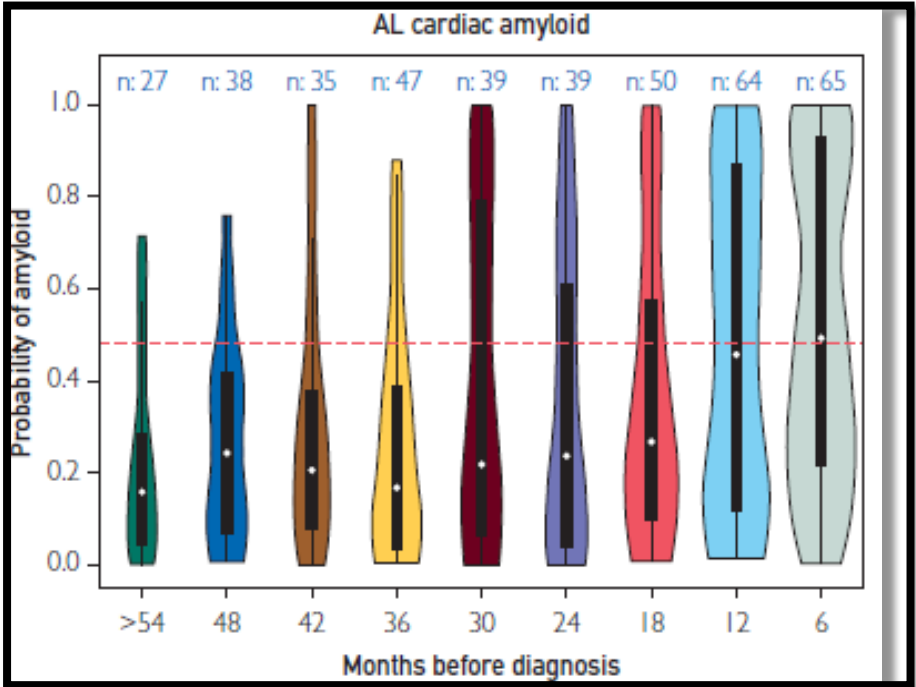
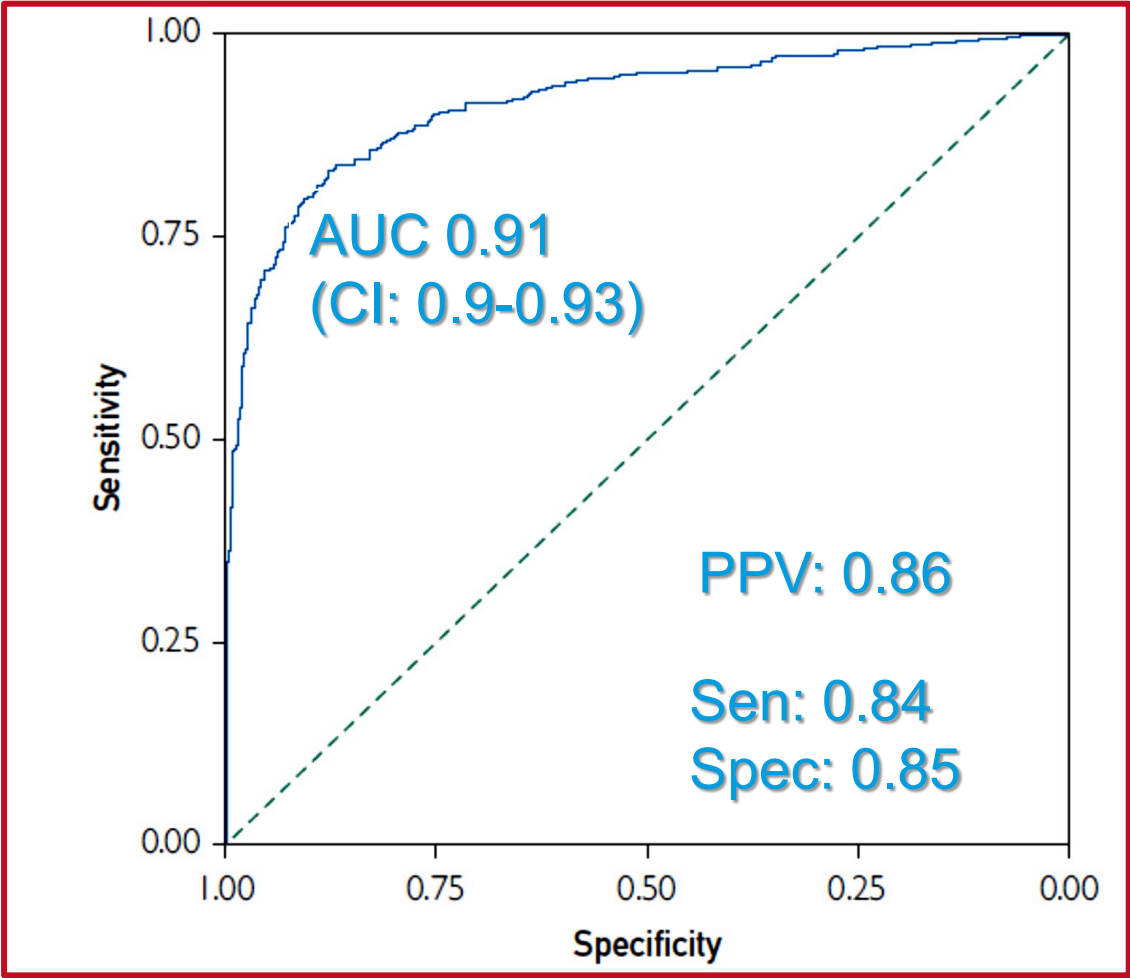


# Artificial Intelligence—Enhanced Electrocardiogram for the Early Detection of Cardiac Amyloidosis

Martha Grogan, MD; Francisco Lopez-Jimenez, MD; Michal Cohen-Shelly, BSc;  
Angela Dispenzieri, MD; Zach I. Attia, PhD; Omar F. Abou Ezzedine, MD, CM, MS;  
Grace Lin, MD; Suraj Kapa, MD; Daniel D. Borgeson, MD; Paul A. Friedman, MD;  
and Dennis H. Murphree Jr, PhD



# AI EKG - Model





# Benefits of Screening

---

- Screening ↑ awareness & recognition
- Implementation of screening → improved diagnostic accuracy
- Earlier diagnosis
  - Initiation of therapy
  - Potential change in clinical course



# CHALLENGES

**Delayed Diagnosis**

**Complex Diagnosis**

**Multi-Organ  
Involvement &  
Complex Therapies**

**DIAGNOSTIC  
ALGORITHMS**



# CHALLENGES

**Delayed Diagnosis**

**Complex Diagnosis**

**Multi-Organ  
Involvement &  
Complex Therapies**

**MULTIDISCIPLINARY  
APPROACH**



# CHALLENGES

**Delayed Diagnosis**

**EDUCATION +  
SCREENING TOOLS**

**Complex Diagnosis**

**DIAGNOSTIC  
ALGORITHMS**

**Multi-Organ  
Involvement &  
Complex Therapies**

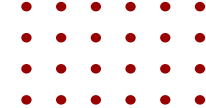
**MULTIDISCIPLINARY  
APPROACH**





# Strengthening Patient Advocacy





# Summary & Key Takeaways

- Suspect amyloid: LV wall thickness  $\geq 12$  mm and clinical clues
- Know the diagnostic algorithm for cardiac amyloid:  
**Rule out AL first!**
- **AL Amyloidosis is a medical emergency!**
- Avoid diagnostic pitfalls (such as interpreting cardiac scintigraphy in the setting of abnormal monoclonal light chain testing)





# Forum Survey Insights & Innovative Solutions to Challenges

**Kevin M. Alexander, MD**

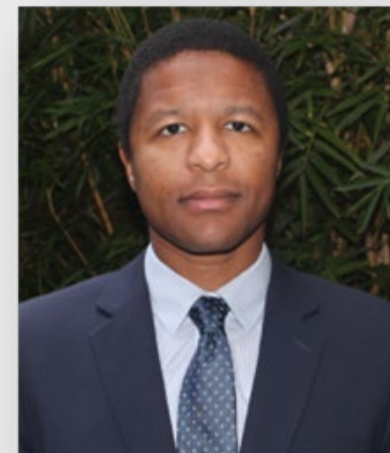
*Assistant Professor of Medicine*

*Advanced Heart Failure and Transplant Cardiology*

Stanford Amyloid Center

Stanford Medicine

@KMAlexanderMD



# Measuring Impact & Guiding Future Action

## Pre Forum Survey Objectives:

- ✓ Assess baseline provider awareness and disease knowledge.
- ✓ Identify existing barriers in the patient pathway.

## Post Forum Survey Objectives:

- ✓ Evaluate forum impact.
- ✓ Gather feedback on forum content and format.

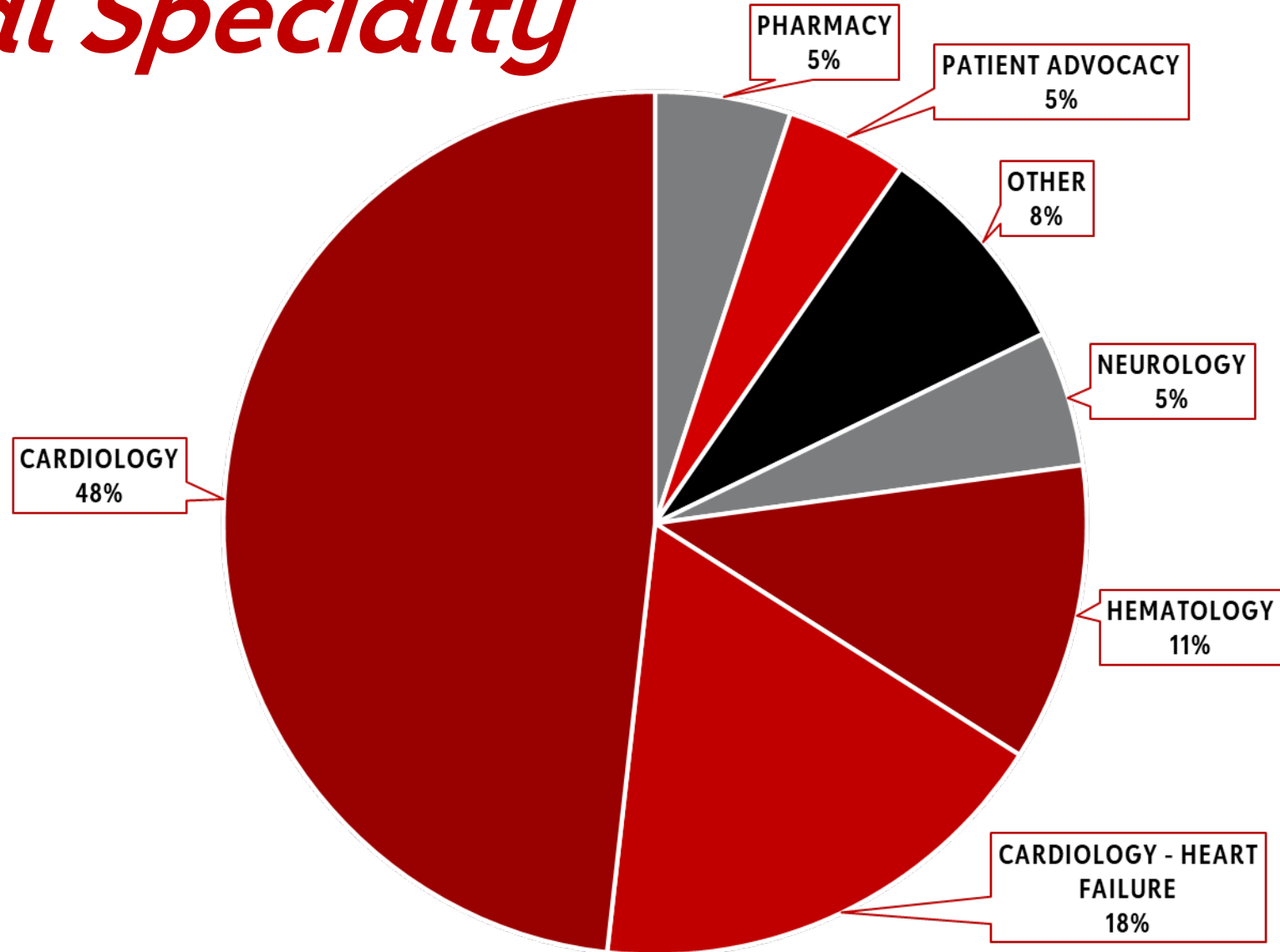


# Forum Attendee Metrics



# Forum Attendance Metrics:

## *Medical Specialty*



181

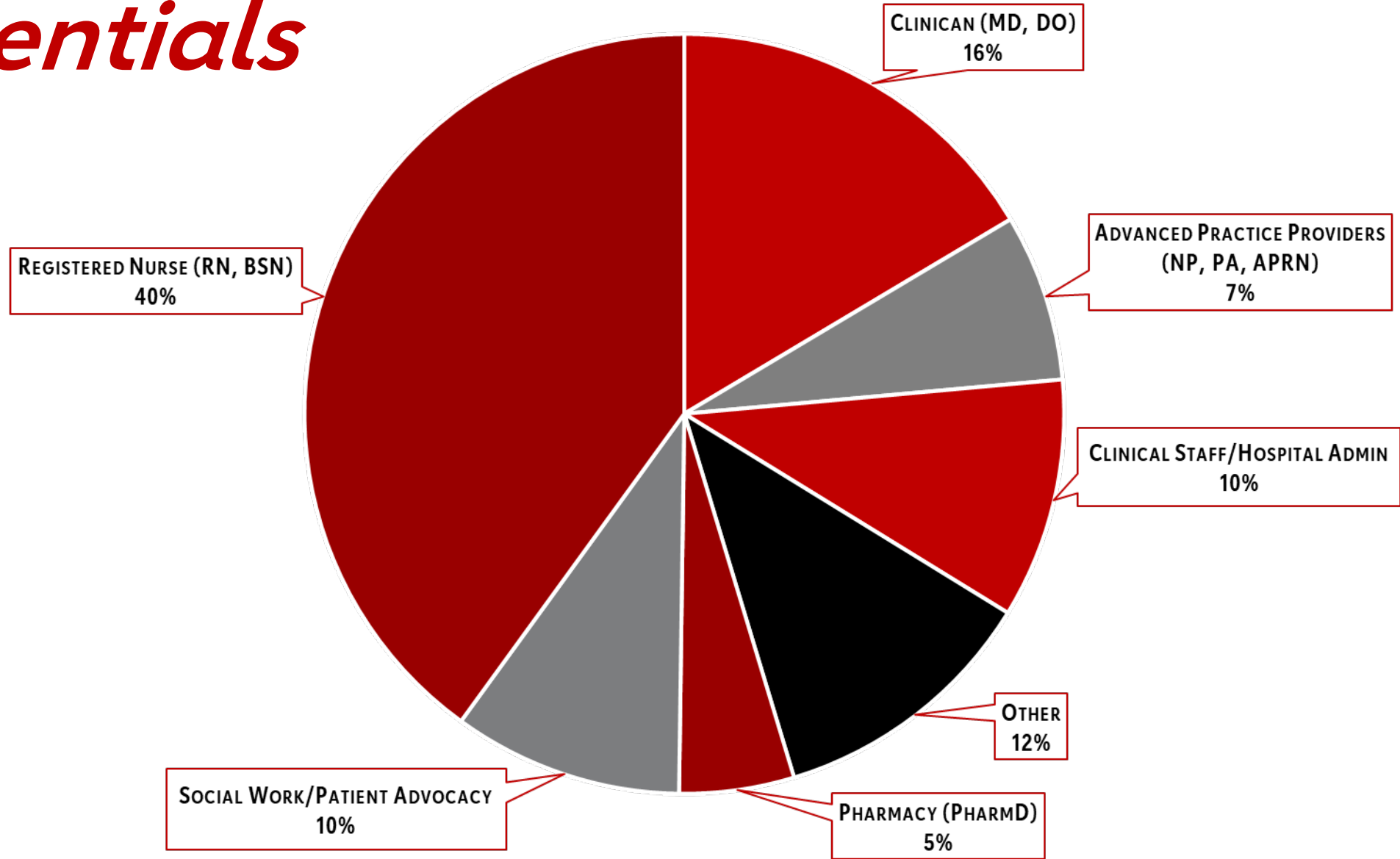
**Other specialties reported:**

Critical Care  
Gastroenterology  
General Practice  
Internal Medicine  
Nephrology



# Forum Attendance Metrics:

## *Credentials*



181

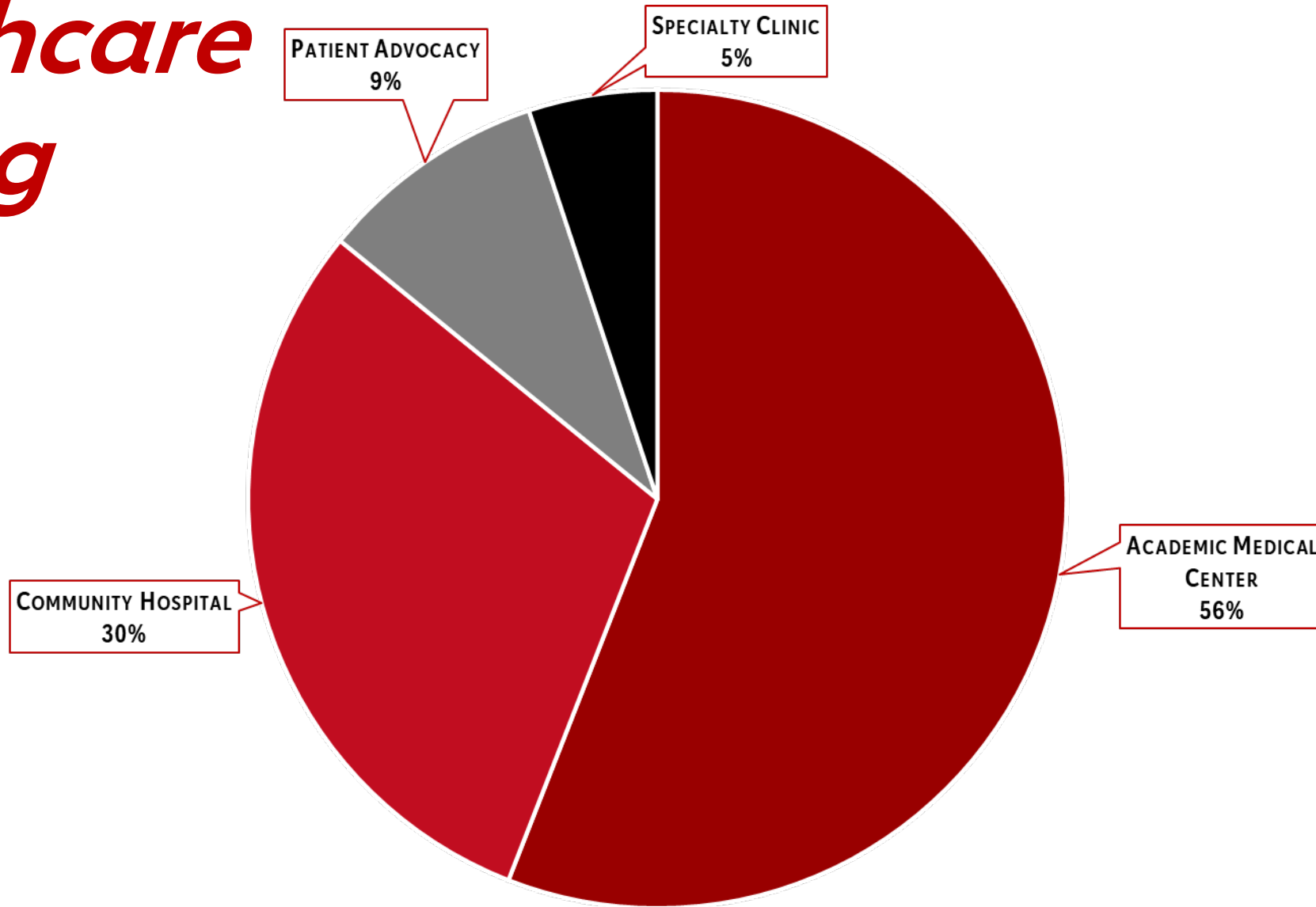
**Other credentials reported:**

PhD Researchers  
Students/ Trainees  
Patients  
Industry Partners



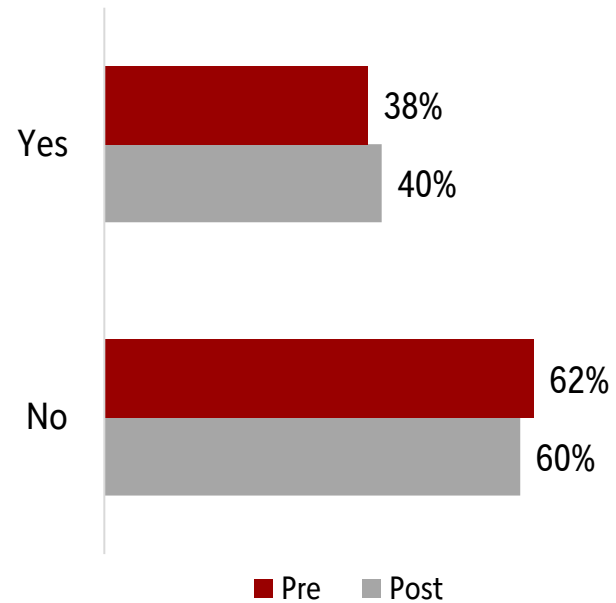
# Forum Attendance Metrics:

## *Healthcare Setting*

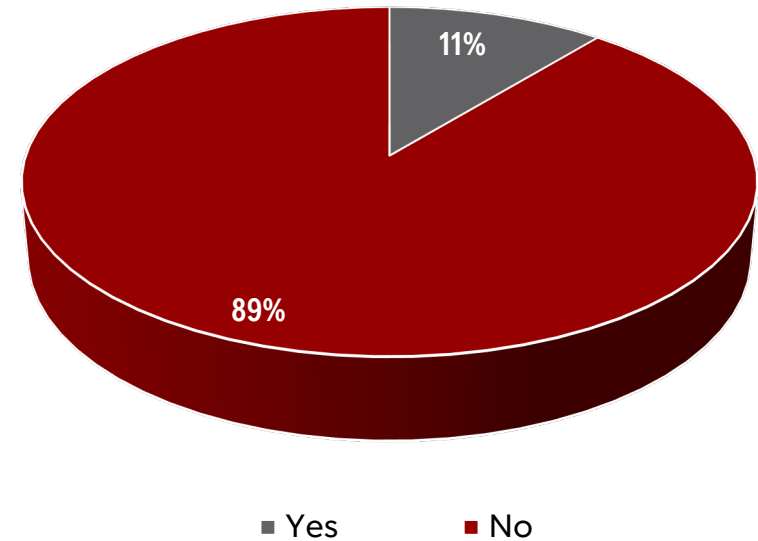


# Institutional Characteristics

Does respondent's organization have an Amyloid Center?



Are you currently involved in any research related to AL Amyloidosis?





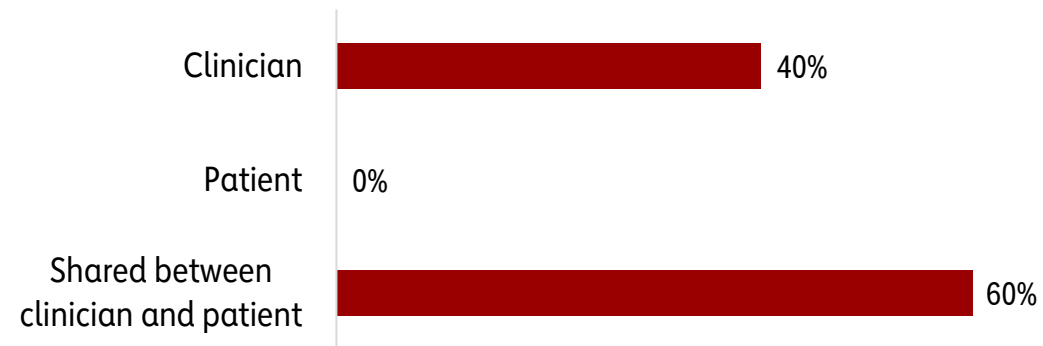
# Disease Management



# Shared Decision-Making and Patient Preparedness

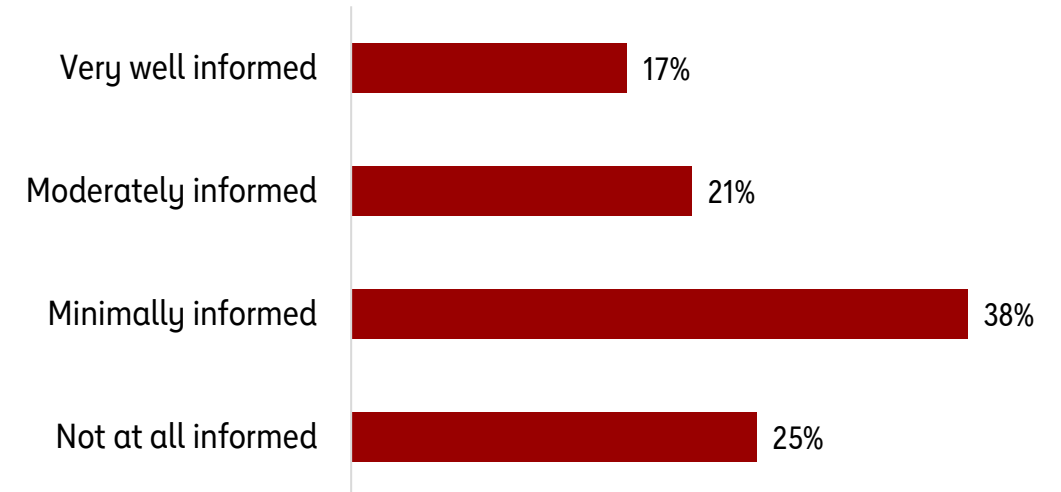
## PRE

In your experience, who typically leads the treatment decision-making process in AL Amyloidosis?



## PRE

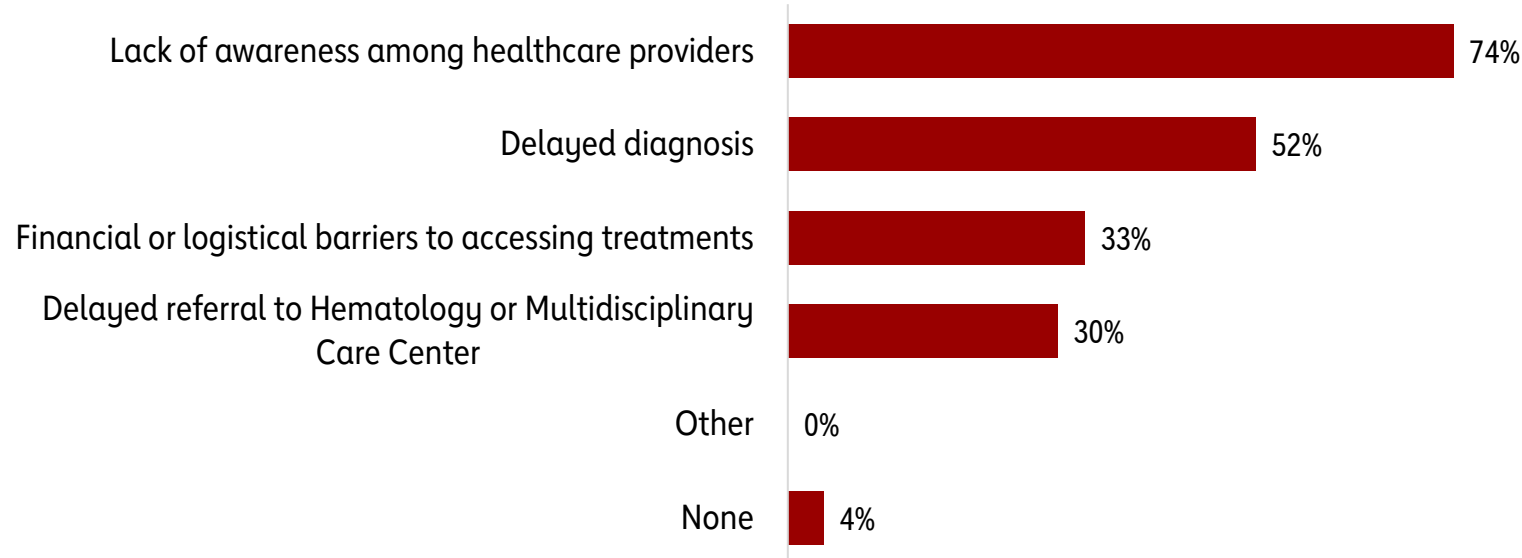
On average, how well informed are patients about their AL Amyloidosis treatment options before discussing them with their clinician?



# Bridging the Knowledge Gap

PRE

What are the main barriers you face in the evaluation and management of AL Amyloidosis patients?



Nearly **3** in **4** providers cited low disease awareness as the top barrier.

It's time to strengthen recognition and remove obstacles to timely care!

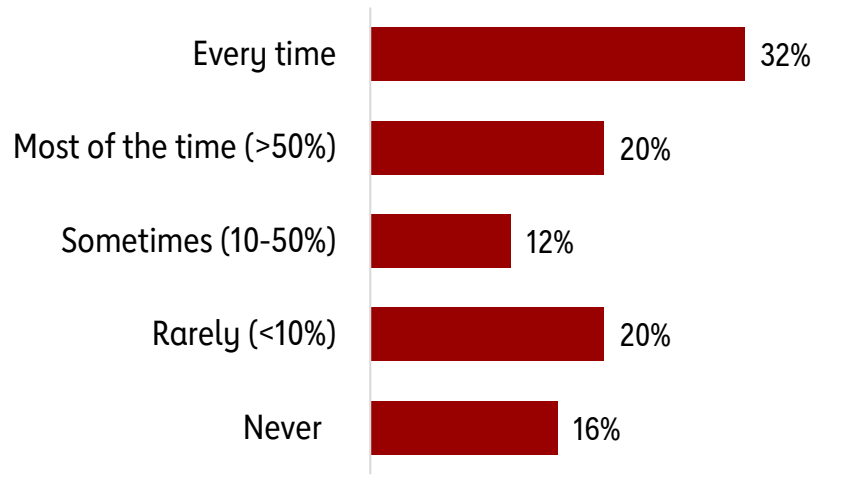




# Evolving Referral Practices

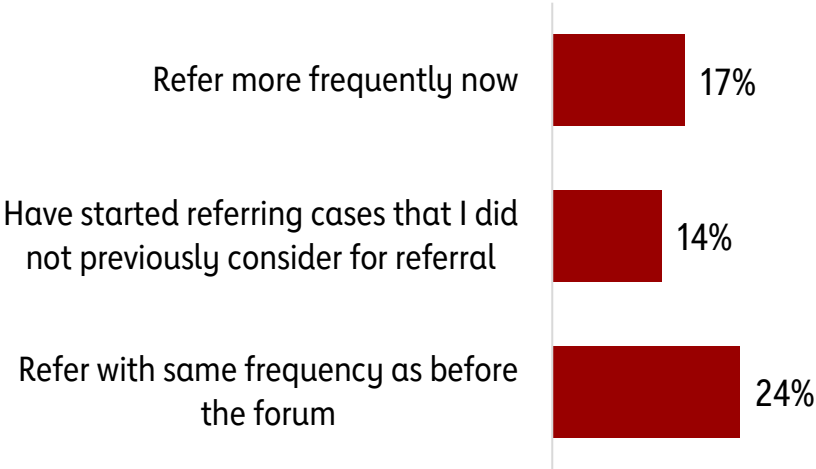
**PRE**

How often do you typically refer a suspected or newly diagnosed AL Amyloidosis patient to a multidisciplinary treatment program?



**POST**

Since attending the forum, what changes have you made or plan to make in your approach to referring suspected or newly diagnosed AL Amyloidosis patients to a multidisciplinary treatment program?



A **third** of respondents have started referring suspected or newly diagnosed patients more frequently or have started referring cases that did not previously consider for referral.

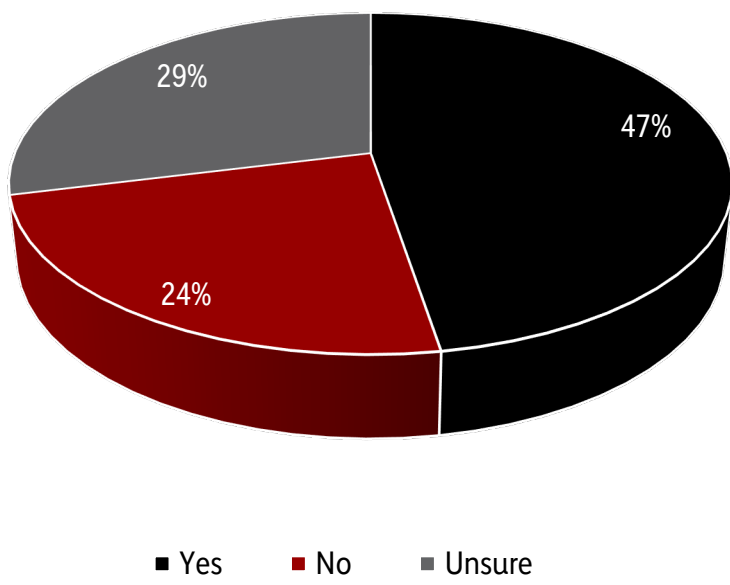




# Institutional Protocols

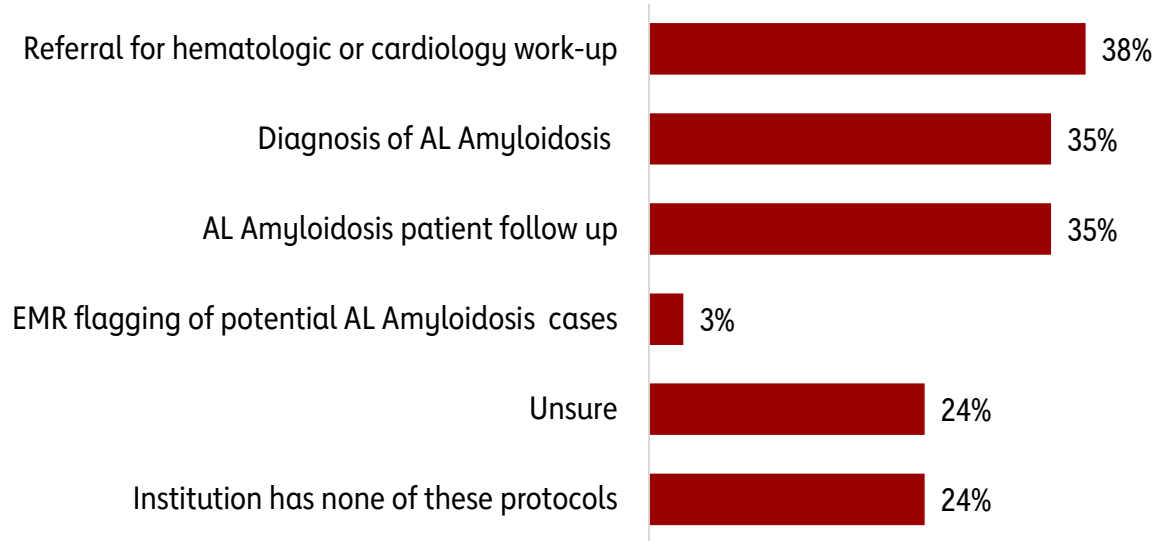
PRE

Does respondent's institution have standard protocols for diagnostic work-up of AL Amyloidosis?



PRE

Respondent's institution has these protocols.

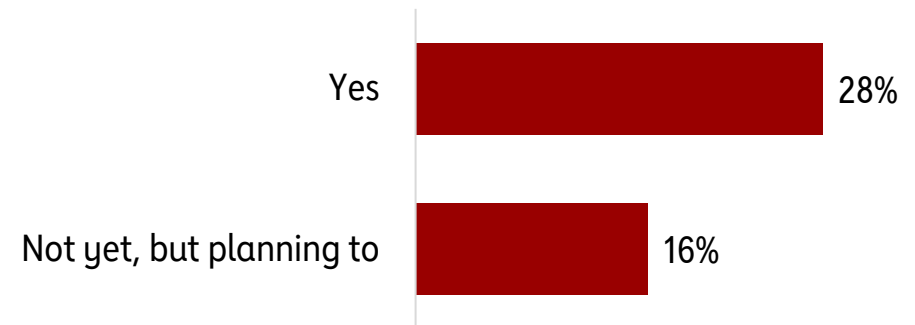


# Turning Awareness Into Action: Institutional Protocols in Motion

**44%** of respondents have either implemented or are planning to implement new diagnostic protocols or referral pathways.

## POST

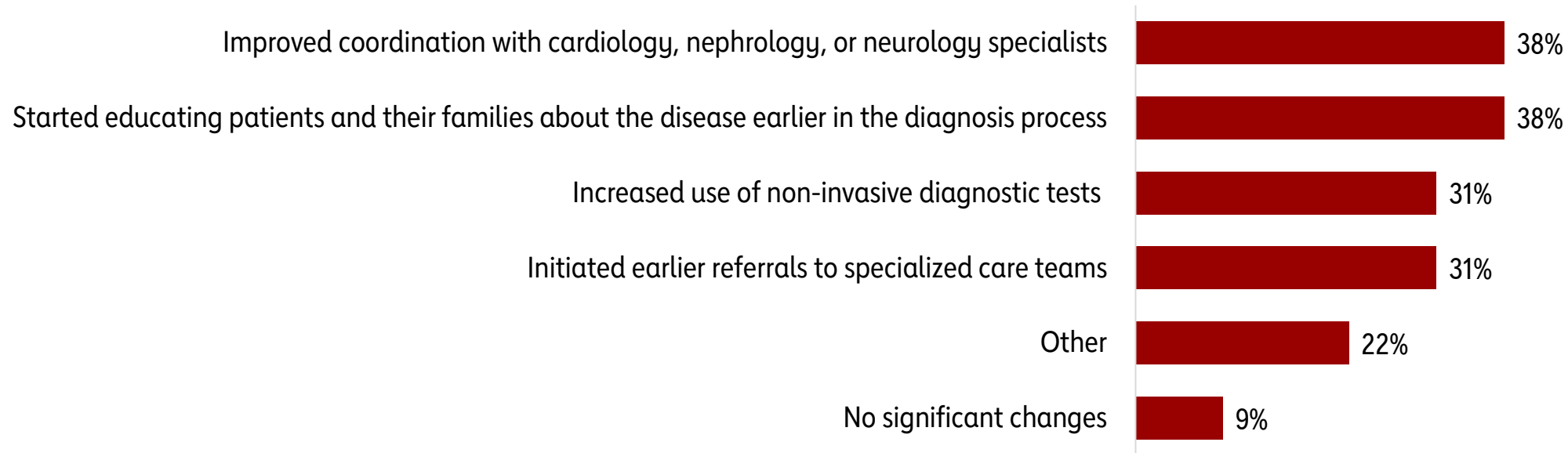
Since attending the forum, have you implemented or considered implementing any new diagnostic protocols or referral pathways for AL Amyloidosis patients at your institution?



# Turning Awareness Into Action: Institutional Protocols in Motion

## POST

Since attending the forum, what changes have you made or plan to make to your clinical approach for managing AL Amyloidosis?

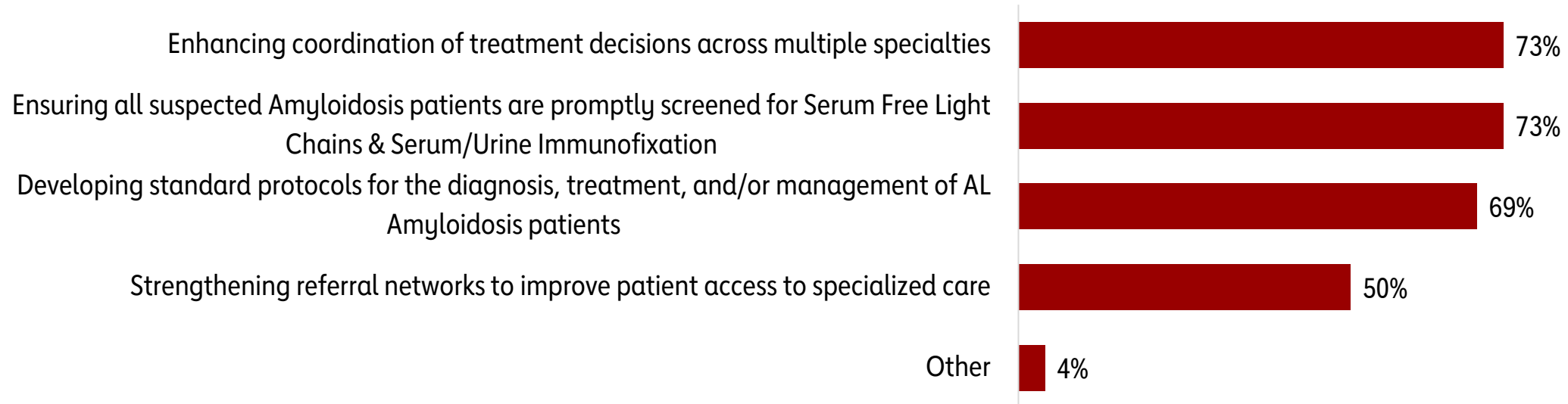




# Turning Awareness Into Action: Institutional Protocols in Motion

## POST

Following the forum, what actions do you plan to take with your team to improve outcomes for patients with AL Amyloidosis?

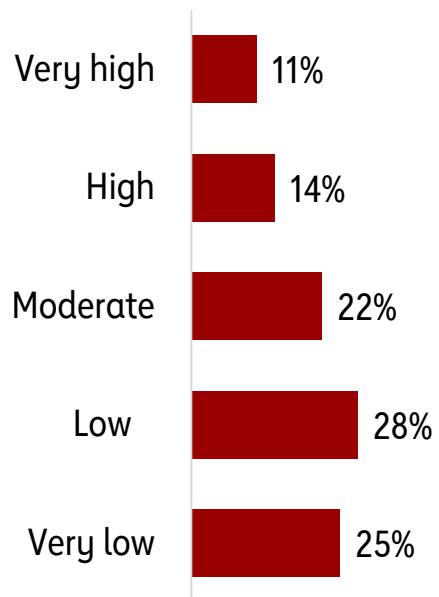


# Disease Confidence & Education Impact

# Pre-Survey: Respondents' Confidence

PRE

Please rate your level of confidence in diagnosing AL Amyloidosis.



Over **half** of respondents reported low or very low confidence in diagnosing AL Amyloidosis prior to the forum.

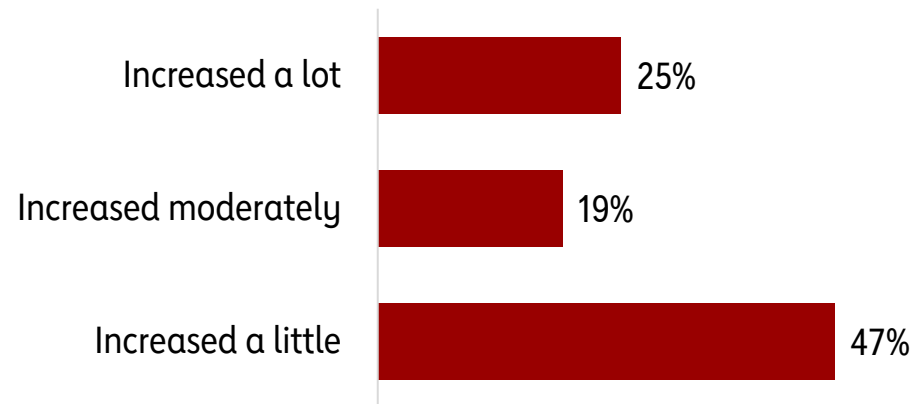
This underscores the need for targeted **education** and **support**.



# Confidence Boost: What Providers Gained from the Forum

## POST

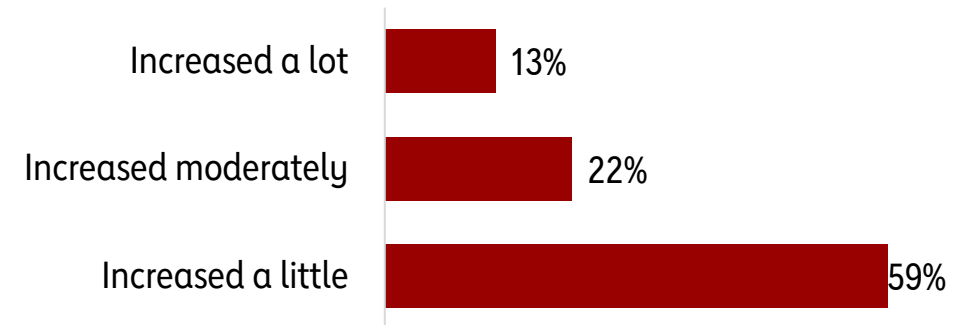
Since attending the AL-Amyloidosis National Patient to Provider Connection Forum, to what extent has your confidence in diagnosing AL Amyloidosis changed?



Nearly all respondents reported an increase in their confidence in diagnosing AL Amyloidosis and a quarter reported their confidence increased “a lot.”

## POST

Since attending the forum, to what extent has your confidence interpreting results from diagnostic tests to confirm AL Amyloidosis changed?

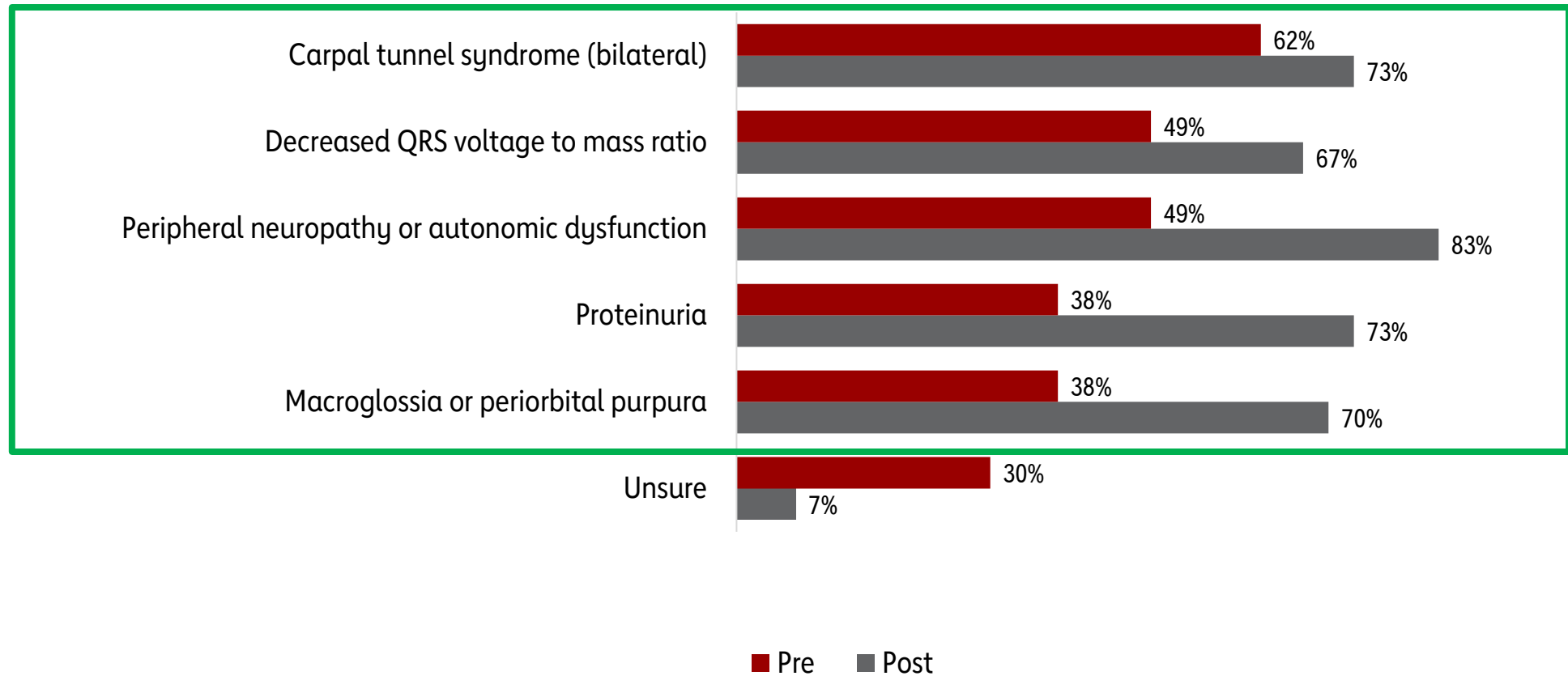


Fewer respondents reported their confidence in interpreting diagnostic tests increased “a lot” or “moderately” (35%) compared to increases in confidence in diagnosing (44%).



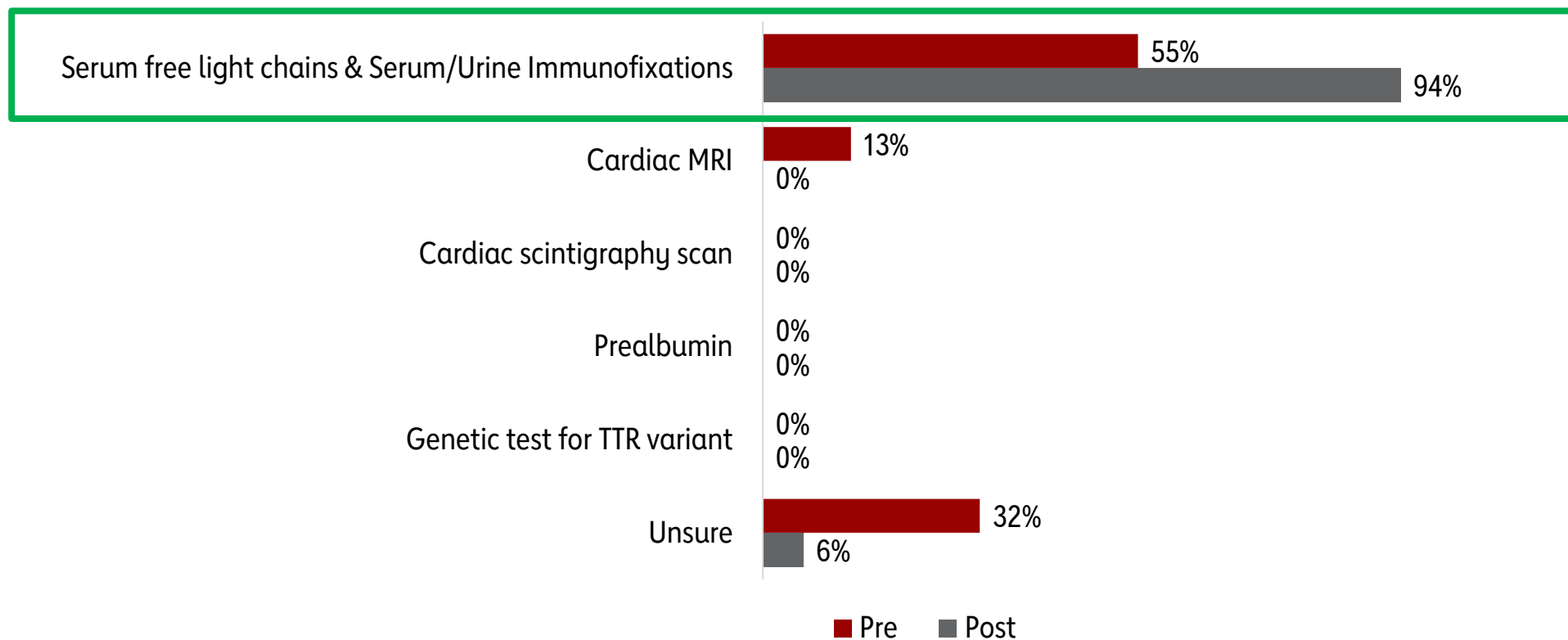
# Pre vs Post: Respondents' Knowledge

What symptoms or combination of clinical presentations most commonly trigger suspicion of AL Amyloidosis?



# Pre vs Post: Respondents' Knowledge

What is the initial test(s) you should order if there is suspicion for AL Amyloidosis?



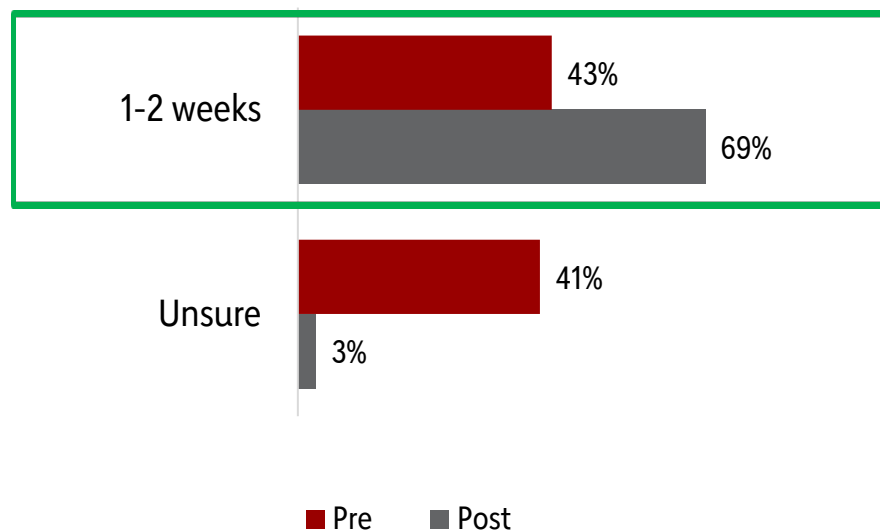
Nearly all post-forum respondents selected the correct initial test compared to just over half of pre-forum respondents.



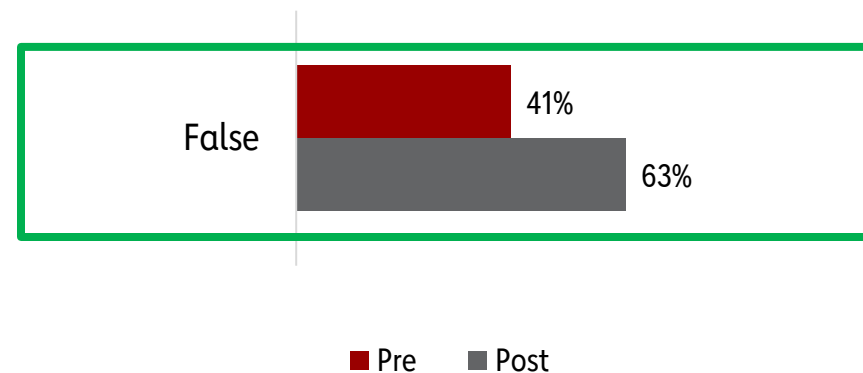
# Pre vs Post: Respondents' Knowledge



Once you suspect AL Amyloidosis, which time frame is most appropriate to complete initial diagnostic testing?



AL Amyloidosis can be diagnosed without a biopsy.





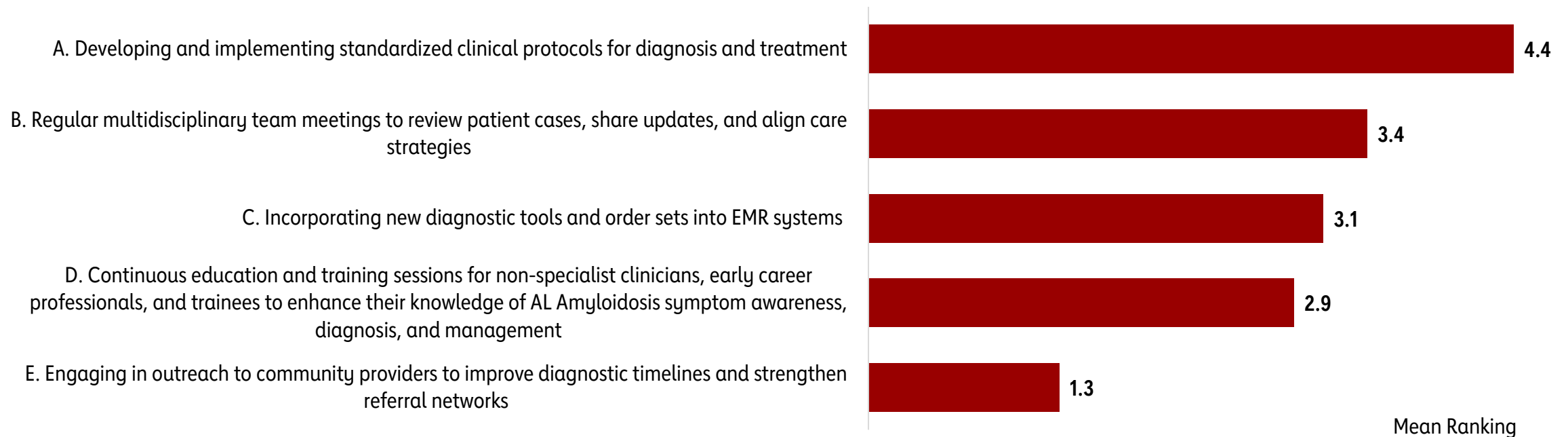
# Respondents' Perspectives



# Respondents' Perspectives

## POST

Which strategies do you think would be most effective in improving the adoption of AL Amyloidosis best practices at your institution? <sup>1</sup>



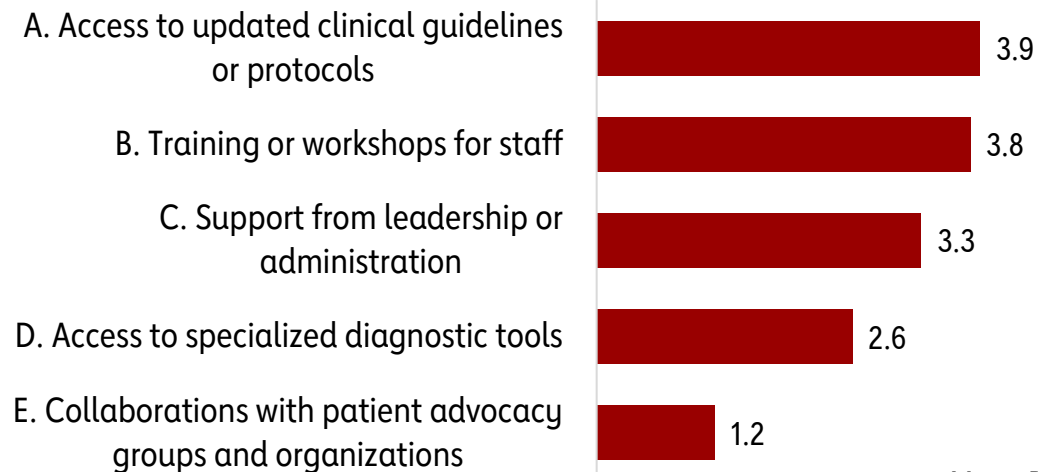
<sup>1</sup> Respondents were instructed to "Please rank from most effective to least effective." 5 Represents the most effective, 1 the least effective. The graph shows the mean ranking given by respondents.



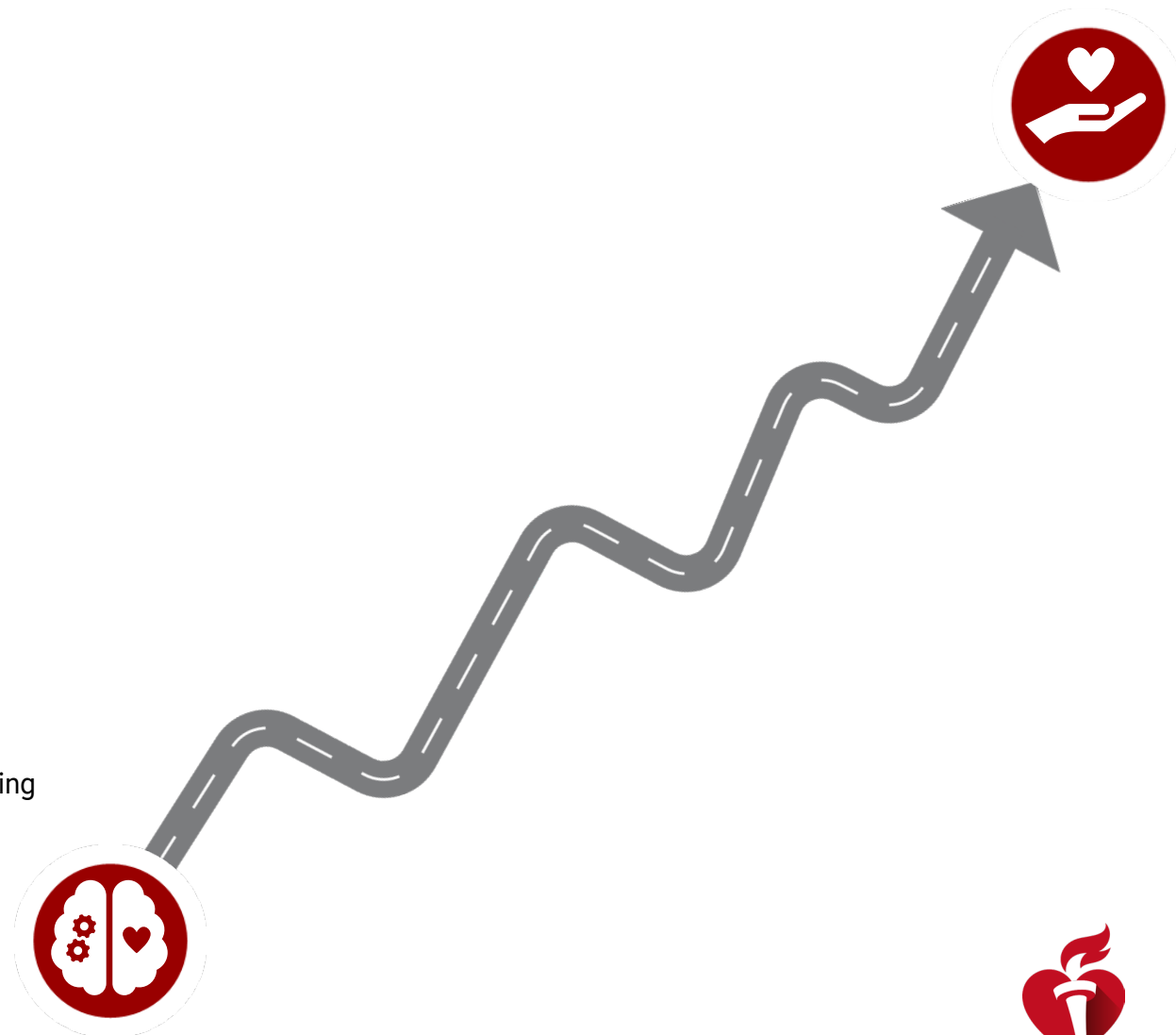
# Respondents' Perspectives

## POST

What type of support or resources would be most helpful in implementing the insights gained from the forum at your institution? <sup>1</sup>

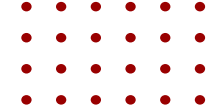


Mean Ranking



<sup>1</sup> Respondents were instructed to "Please rank from most helpful to least helpful." 5 Represents the most helpful, 1 the least helpful. The graph shows the mean ranking given by respondents.





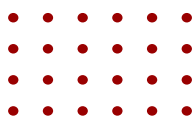
# Summary & Key Takeaways

Forum insights show measurable improvements and ongoing needs in:

- ✓ **Disease awareness**
- ✓ **Provider knowledge**
- ✓ **Clinical confidence**
- ✓ **Institutional protocols**

Critical gaps still exist –continued action is **essential**.

Let this data spark your next conversation, referral, or care initiative.





# AL Amyloidosis Educational Toolkit Launch

**Mathew Maurer, MD**

*Professor of Medicine,  
Arnold and Arlene Goldstein Professor of  
Cardiology, NewYork-Presbyterian/Columbia  
University Irving Medical Center*



# AL Amyloidosis Educational Toolkit

- ✓ Quick Reference Guide
- ✓ Clinician Pocket Card
- ✓ Patient Advocacy Resources
- ✓ Educational Recordings & Presentation Materials

**Toolkit & Resources can be accessed at:**

<https://www.heart.org/AL-Amyloidosis>



# AL Amyloidosis Educational Toolkit



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## AL Amyloidosis Educational Toolkit



# Quick Reference Guide



## AL Amyloidosis Quick Reference Guide

### Disease Overview

**AL Amyloidosis (Light Chain)** is a rare but life-threatening disease caused by abnormal plasma cells producing misfolded light chain proteins. These proteins form amyloid fibrils that deposit in organs - most commonly affecting: Heart, Kidneys, Liver, Gastrointestinal system, Nervous system. **This leads to progressive and often irreversible organ dysfunction.**

**Early suspicion and testing are critical.** AL Amyloidosis often presents with vague symptoms, and delays in diagnosis can result in severe organ failure.

**Diagnosis should be treated as a medical emergency** as rapid intervention is essential to prevent further damage. Treatment focuses on halting light chain production through: Chemotherapy, Monoclonal antibodies, Stem cell transplantation.

**A high index of suspicion and prompt action can significantly improve patient outcomes.**

### Key Diagnostic Testing

#### Initial Screening Tests

- Serum free light chains (kappa & lambda)
- Serum electrophoresis with immunofixation
- Urine electrophoresis with immunofixation
- Troponin T & NT-proBNP
- Electrocardiogram
- Echo (with strain imaging)/Cardiac MRI (with and without contrast)

#### Further Diagnostic Testing

- Abdominal fat pad biopsy
- Bone marrow biopsy

Diagnosis confirmation requires a tissue biopsy with Congo red staining to detect amyloid deposits:

- Abdominal fat pad biopsy
- Bone marrow biopsy

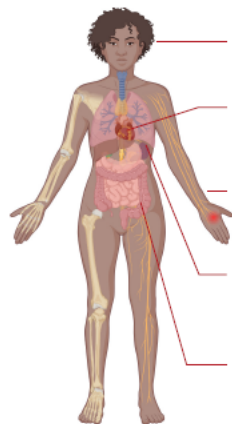
Note: If both biopsies are negative but clinical suspicion for AL Amyloidosis remains high, consider biopsy of the affected organ.

### Different Diagnosis

#### Abnormal Monoclonal Testing Diagnosis Considerations

- Monoclonal Gammopathy of undetermined significance
- Multiple Myeloma, Smoldering Multiple Myeloma, or Light Chain Smoldering Multiple Myeloma
- Waldenström Macroglobulinemia
- POEMS Syndrome

### Clinical Clues



**General:**  
Weakness, unexplained fatigue, macroglossia

**Hematologic:**  
Easy bruising, periorbital purpura (raccoon eyes)

**Cardiac:**  
Dyspnea, hypotension, edema, arrhythmias, increased for L-Ventricular wall thickness

**Neurologic:**  
Peripheral neuropathy, carpal tunnel syndrome, autonomic dysfunction

**Renal:**  
Proteinuria, nephrotic syndrome, kidney dysfunction

**Gastrointestinal:**  
Significant unintentional weight loss, diarrhea/constipation, malabsorption, unexplained GI bleeding, hepatomegaly

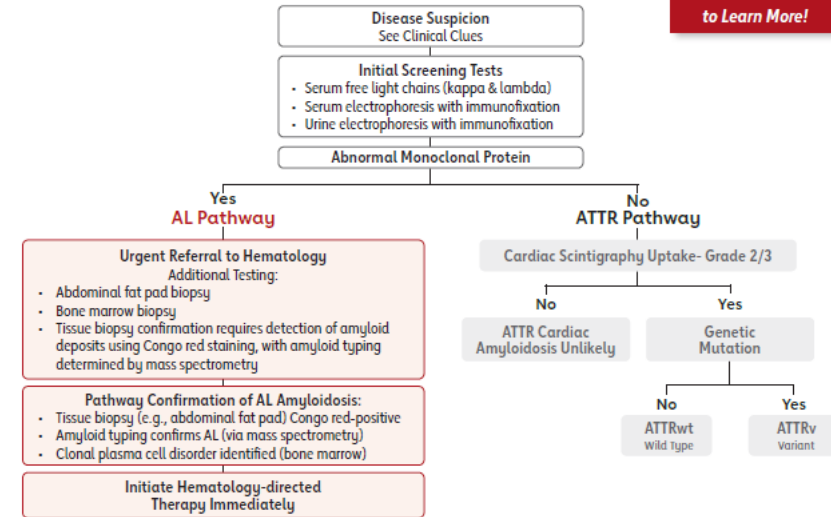
Front

## AL Amyloidosis Quick Reference Guide



Scan or Click Here to Learn More!

### Diagnosing Amyloidosis



### Referral Guidance

- Refer suspected AL Amyloidosis patients to an amyloidosis center when possible.
- If an amyloidosis center is unavailable, prompt consultation with hematology and cardiology is essential.
- A diagnosis of AL Amyloidosis is a medical emergency that demands timely evaluation and multidisciplinary collaboration to ensure the best possible outcomes.


### Patient Advocacy and Support Resources



Back


# Clinician Pocket Card


Front


**American Heart Association.**


**AL Amyloidosis**  
Clinician Pocket Guide


### Clinical Clues


**General:**  
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**Gastrointestinal:**  
Significant unintentional weight loss, diarrhea/constipation, malabsorption, unexplained GI bleeding, hepatomegaly

**Renal:**  
Proteinuria, nephrotic syndrome, kidney dysfunction

### Suspect Amyloidosis?

Act Swiftly with These Tests

#### Initial Screening Tests

---

Serum free light chains (kappa & lambda)

---

Serum electrophoresis with immunofixation

---

Random urine electrophoresis with immunofixation

---

Troponin T & NT-proBNP

---

Electrocardiogram


---

Echo (with strain imaging)/Cardiac MRI (with and without contrast)

---

Back

**AL Amyloidosis**  
Clinician Pocket Guide


  
[Scan or Click Here to Learn More!](#)

### What is AL Amyloidosis?


AL Amyloidosis (Light Chain) is a rare plasma cell disorder marked by misfolded immunoglobulin light chains forming amyloid fibrils that deposit in vital organs, causing progressive dysfunction and requiring specialized, multidisciplinary care.


### Early Recognition is Key. Refer Early!

- Refer to an amyloidosis center, if possible, for comprehensive care.
- If an amyloidosis center is unavailable, consult with hematology and cardiology ASAP.
- **Multidisciplinary collaboration is critical to improve outcomes!**



**Questions or Referrals? Reach Out To:**  
Contact Info:

 **ALEXION** The AL Amyloidosis Toolkit is proudly supported by Alexion, AstraZeneca Rare Disease.



# How this Toolkit Helps?!



**From Awareness to Action — Tools That Make a Difference.**



**CALL TO ACTION**


**L**

**7**



# [www.heart.org/AL-Amyloidosis](http://www.heart.org/AL-Amyloidosis)



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## AL Amyloidosis Educational Toolkit



## Webinar & Forum Recordings

Access recorded sessions from our National AL-Amyloidosis Patient-to-Provider Connection Forum, featuring leading experts, patient advocacy groups, real patient stories, and actionable strategies to improve diagnosis and care delivery.

- **National AL-Amyloidosis Patient-to-Provider Connection Forum - March 12, 2025**
  - [Presentation Slides \(PDF\)](#)



**Q & A**





# Thank you for joining us today!

Recordings of today's webinar and toolkit materials will be enduring resources on

[www.heart.org/AL-Amyloidosis](http://www.heart.org/AL-Amyloidosis)

