

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 12th
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

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.

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

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Meeting ID: 882 3297 2553

Passcode: 595964





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 Alexion, Astra Zeneca Rare Disease
for being a proud supporter of the American Heart Association.**



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

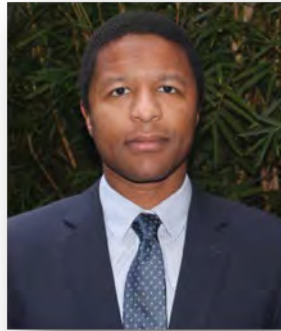


Tammy Reideler, MSN, RN, OCN

Mayo Clinic Hospital - FL
Acute Leukemia and Amyloidosis Nurse
Navigator



AL-Amyloidosis Expert Collaborative Leadership



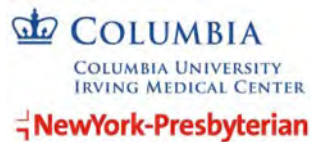
Kevin M. Alexander, MD

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

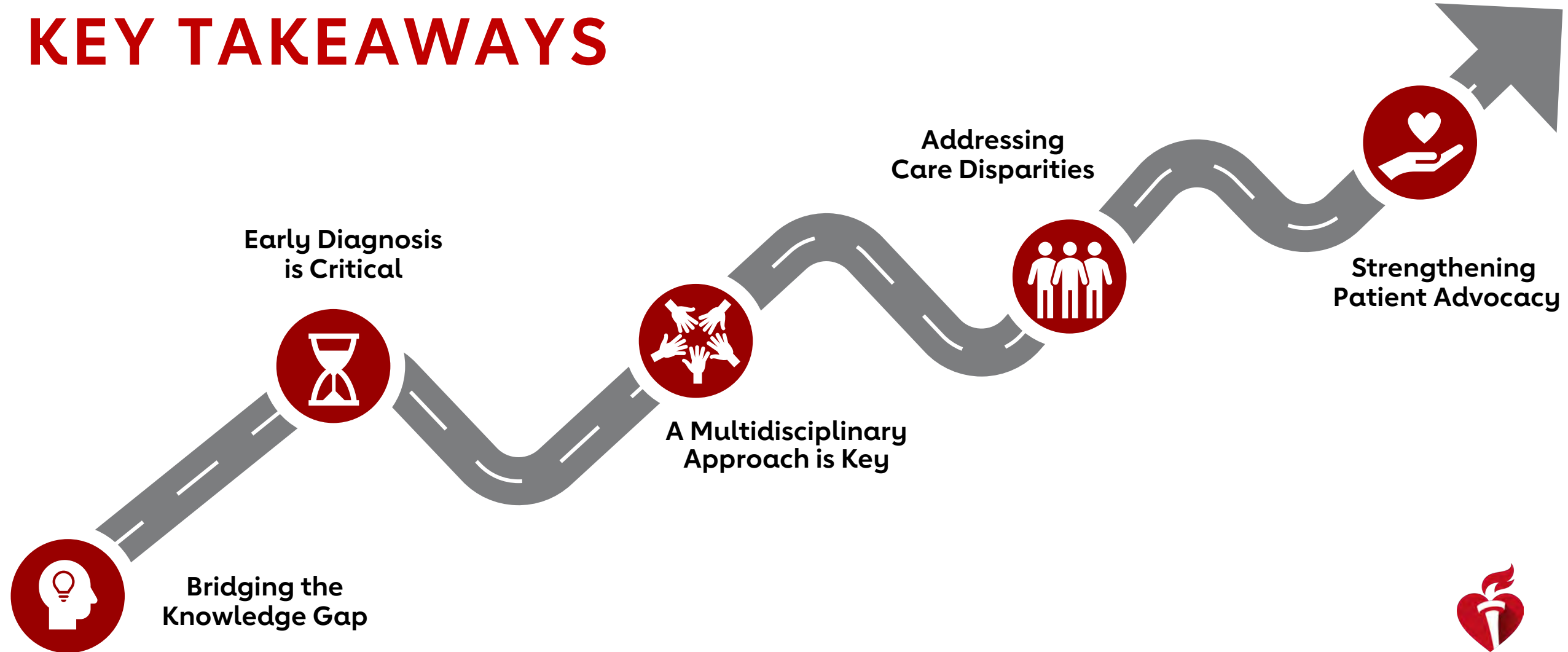
Division of Advanced Heart Failure and Transplantation

Mayo Clinic Florida



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

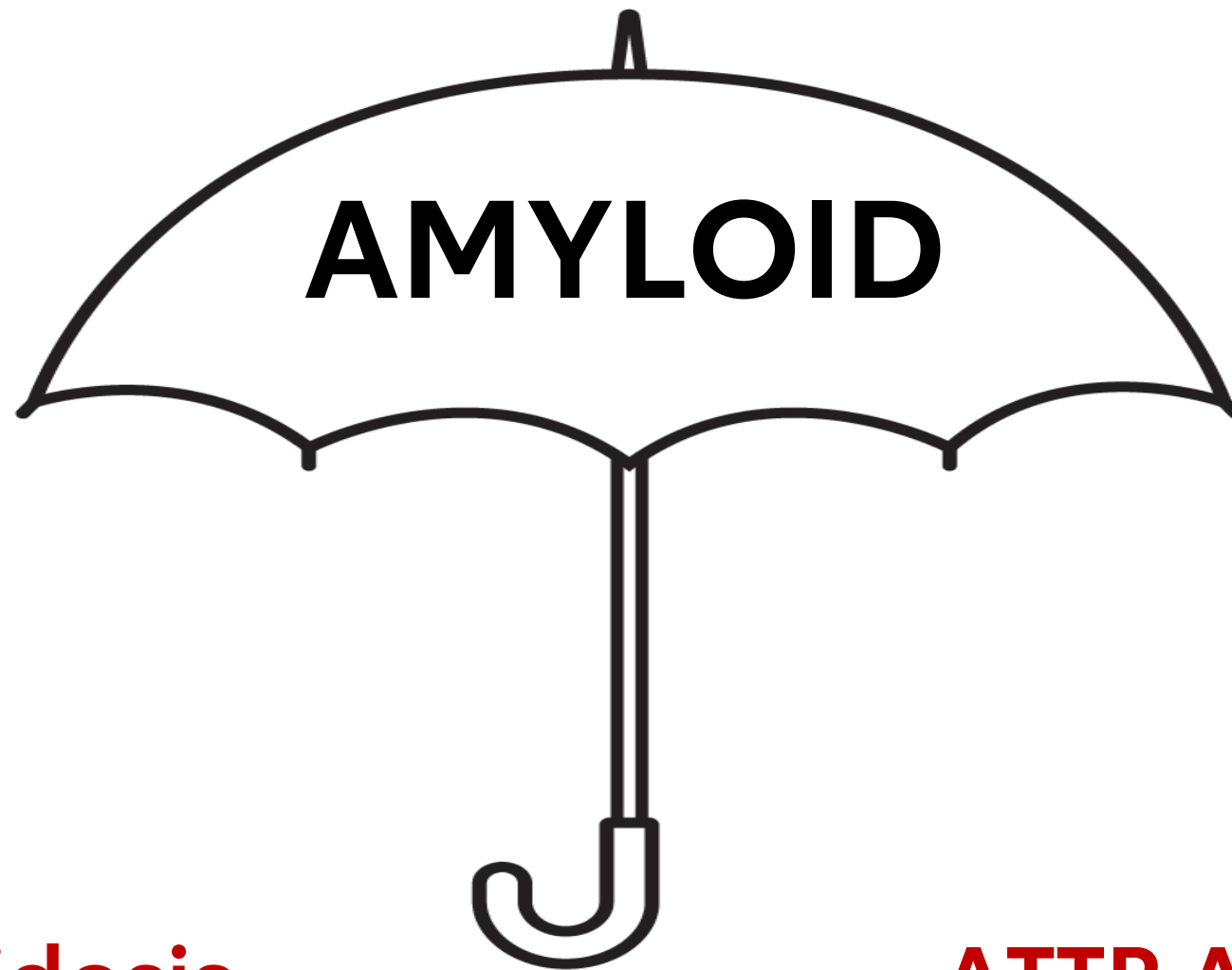
KEY TAKEAWAYS





AL-Amyloidosis Disease Overview





AL Amyloidosis

Protein: Immunoglobulin light chain

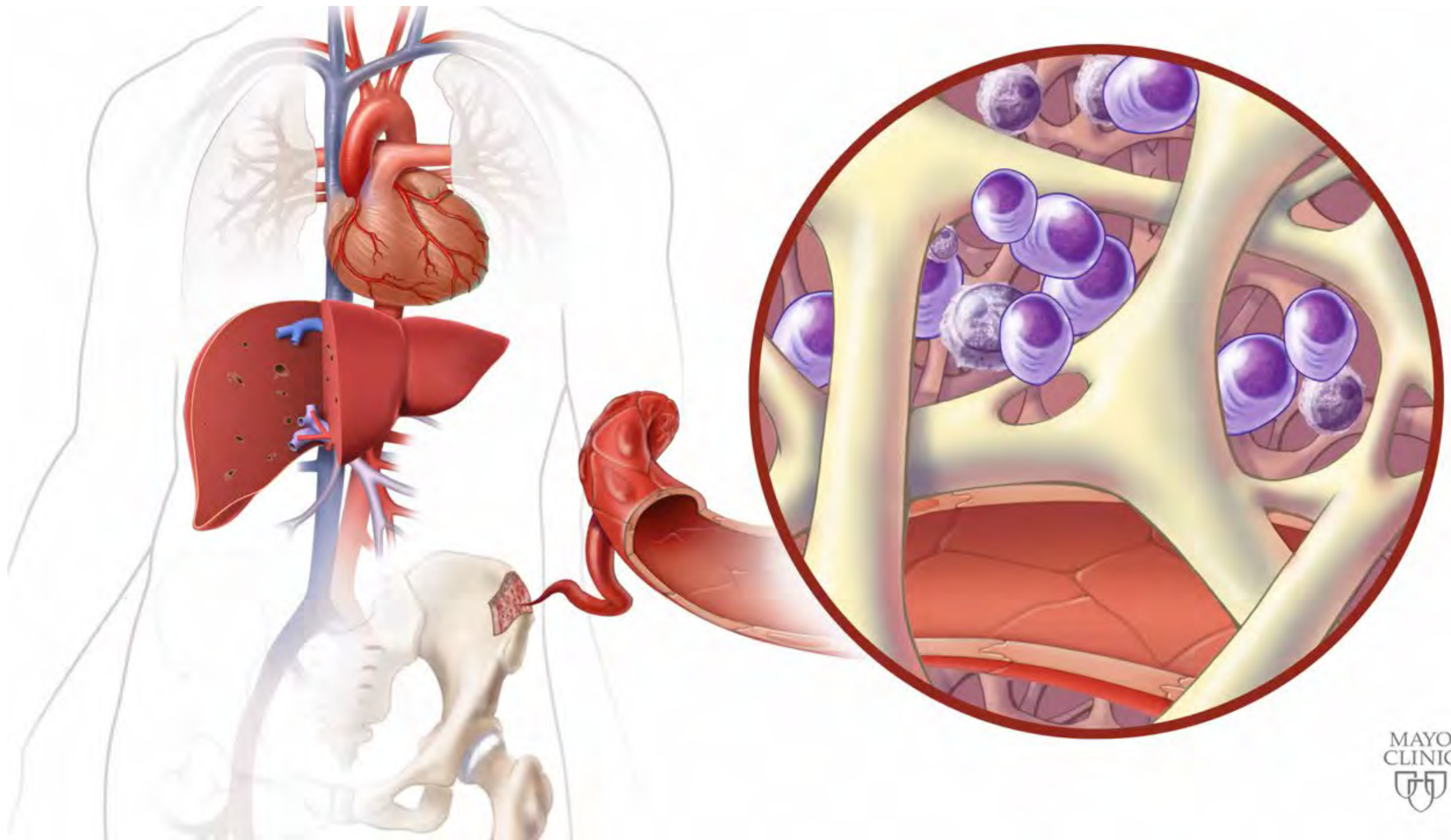
Protein Factory: Plasma Cells in bone marrow

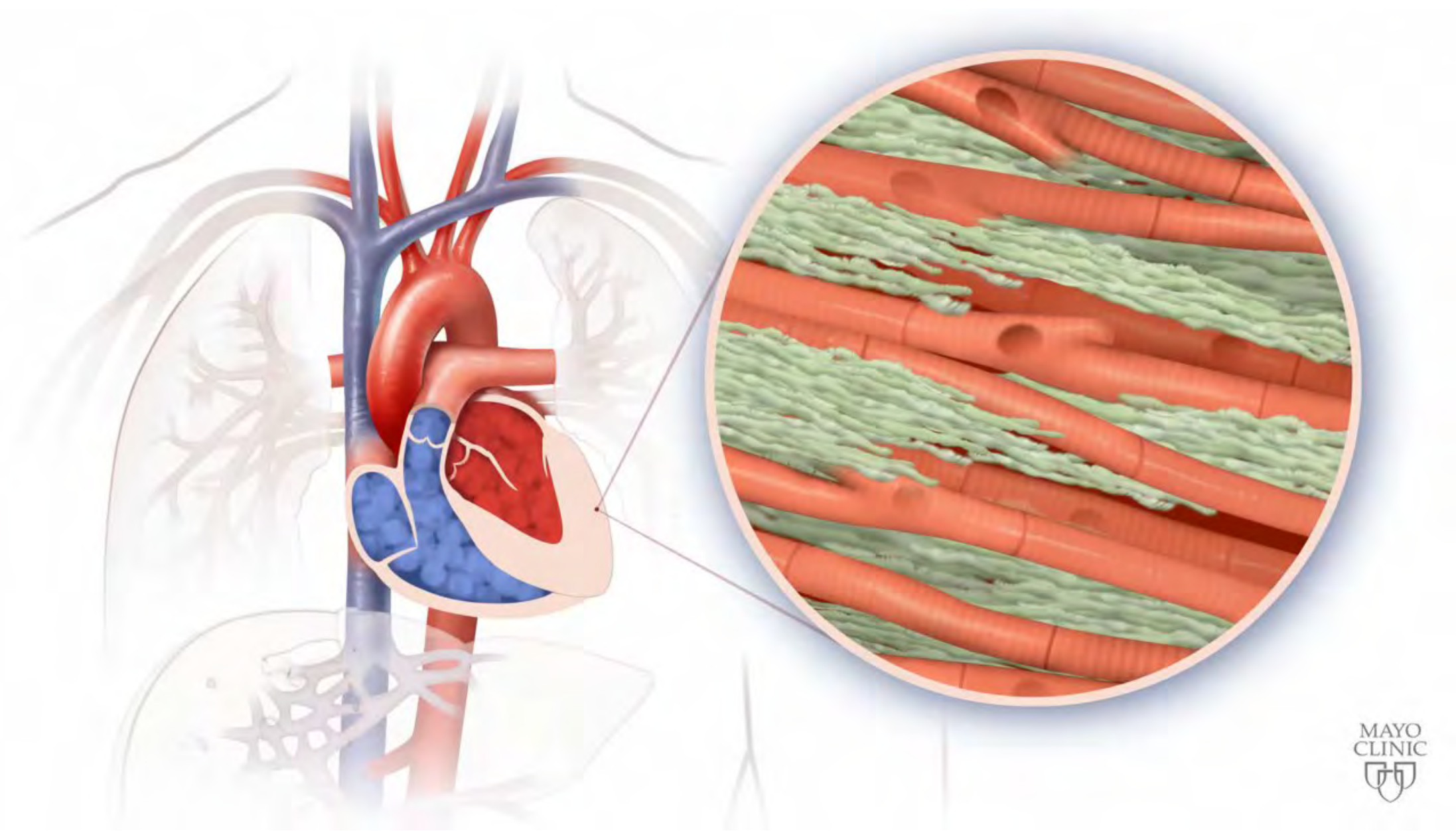
ATTR Amyloidosis

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

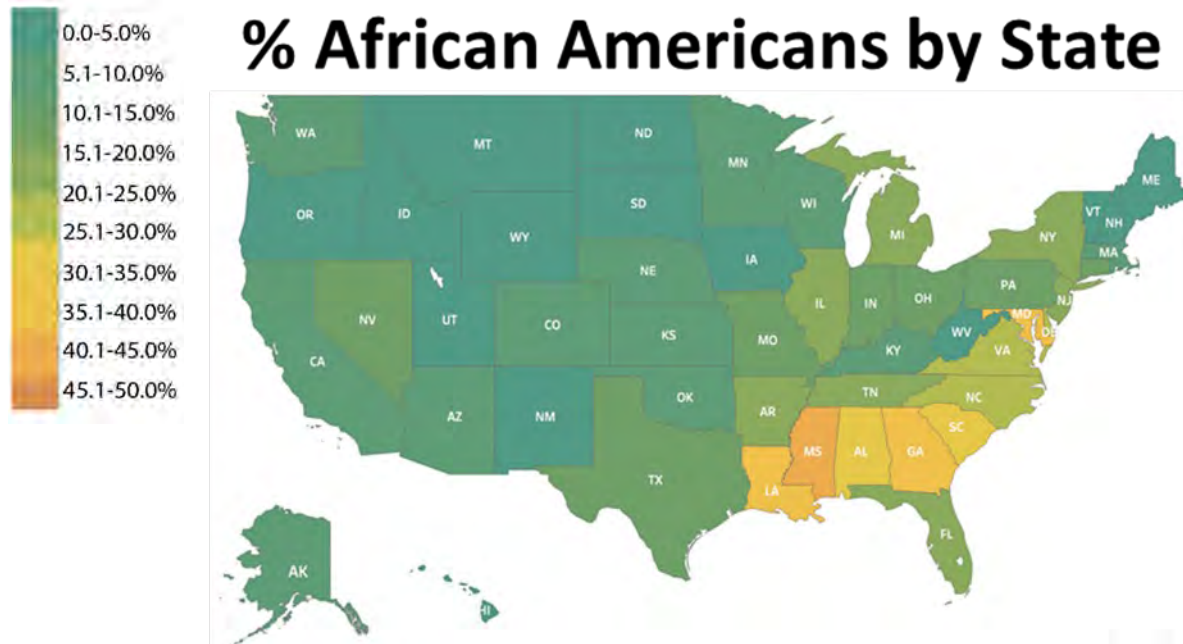




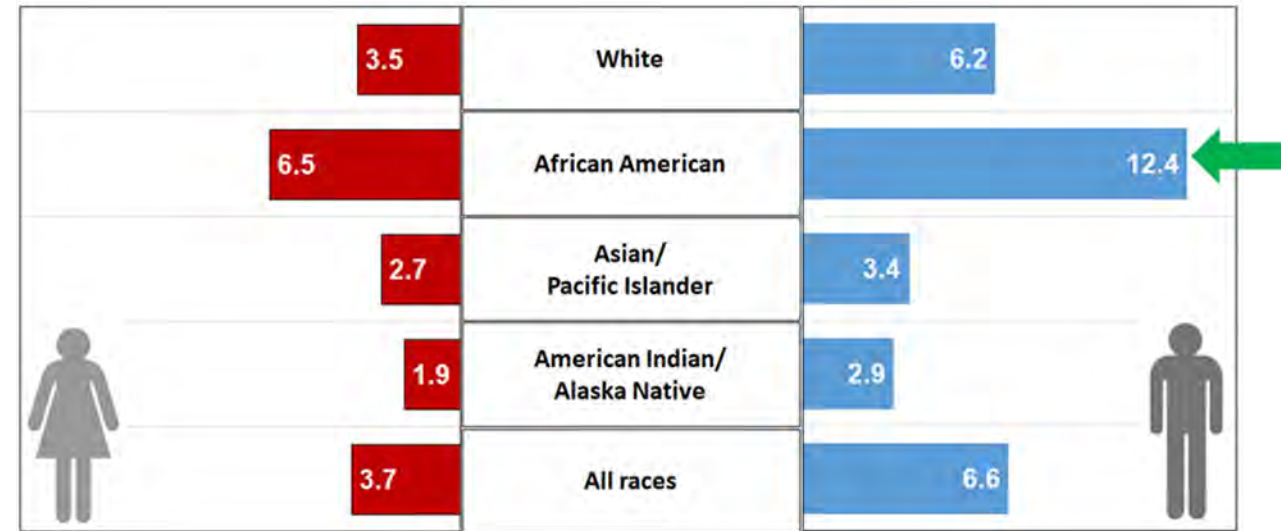
Addressing Care Disparities



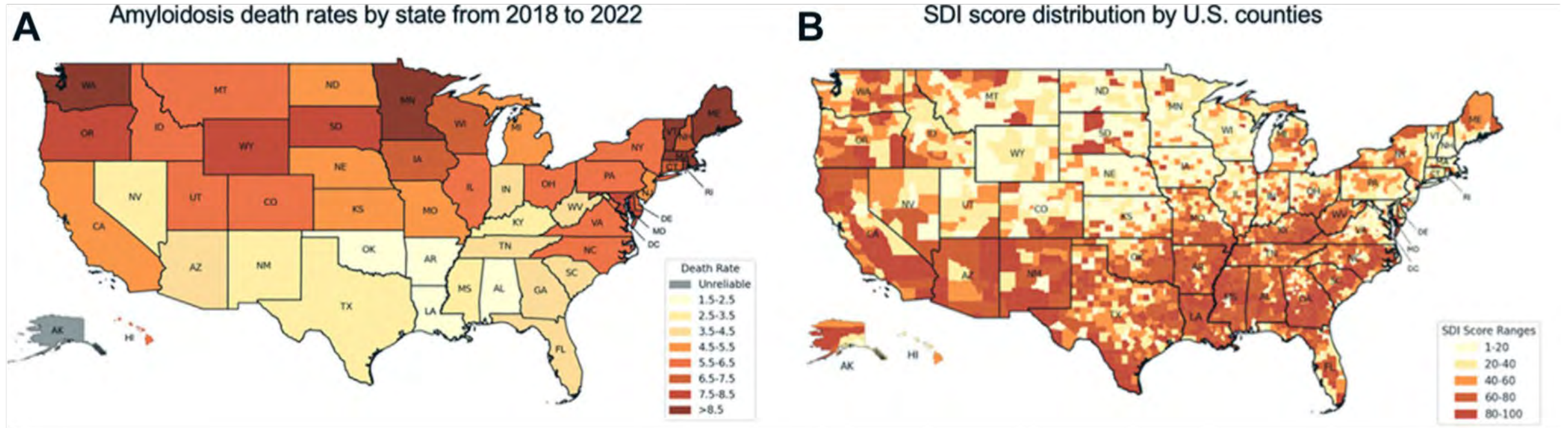
Disproportionate Impact and Underdiagnosis in Black Individuals



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 ≥ 12 mm



2. ≥ 1 Clinical Clues



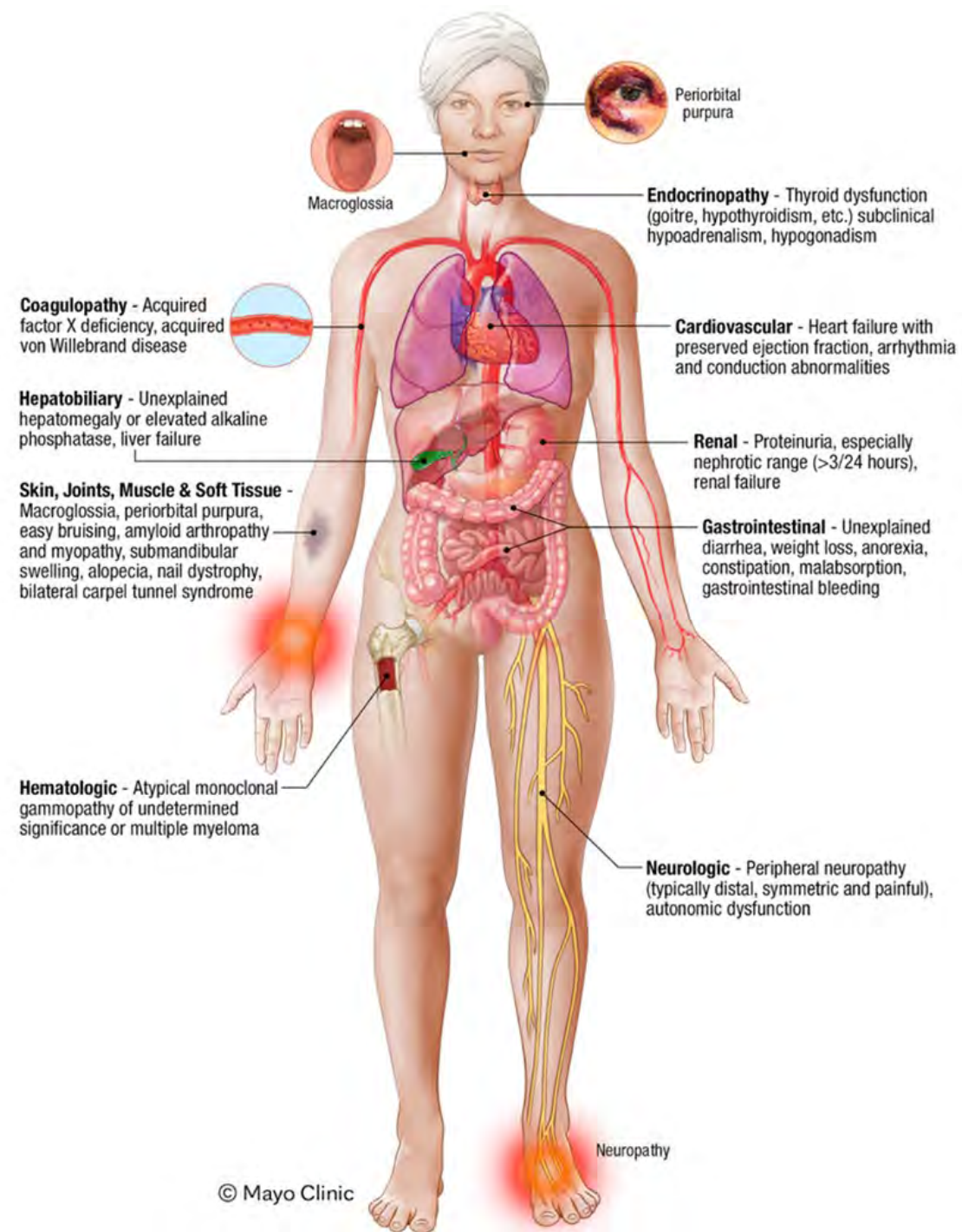


Clinical Clues

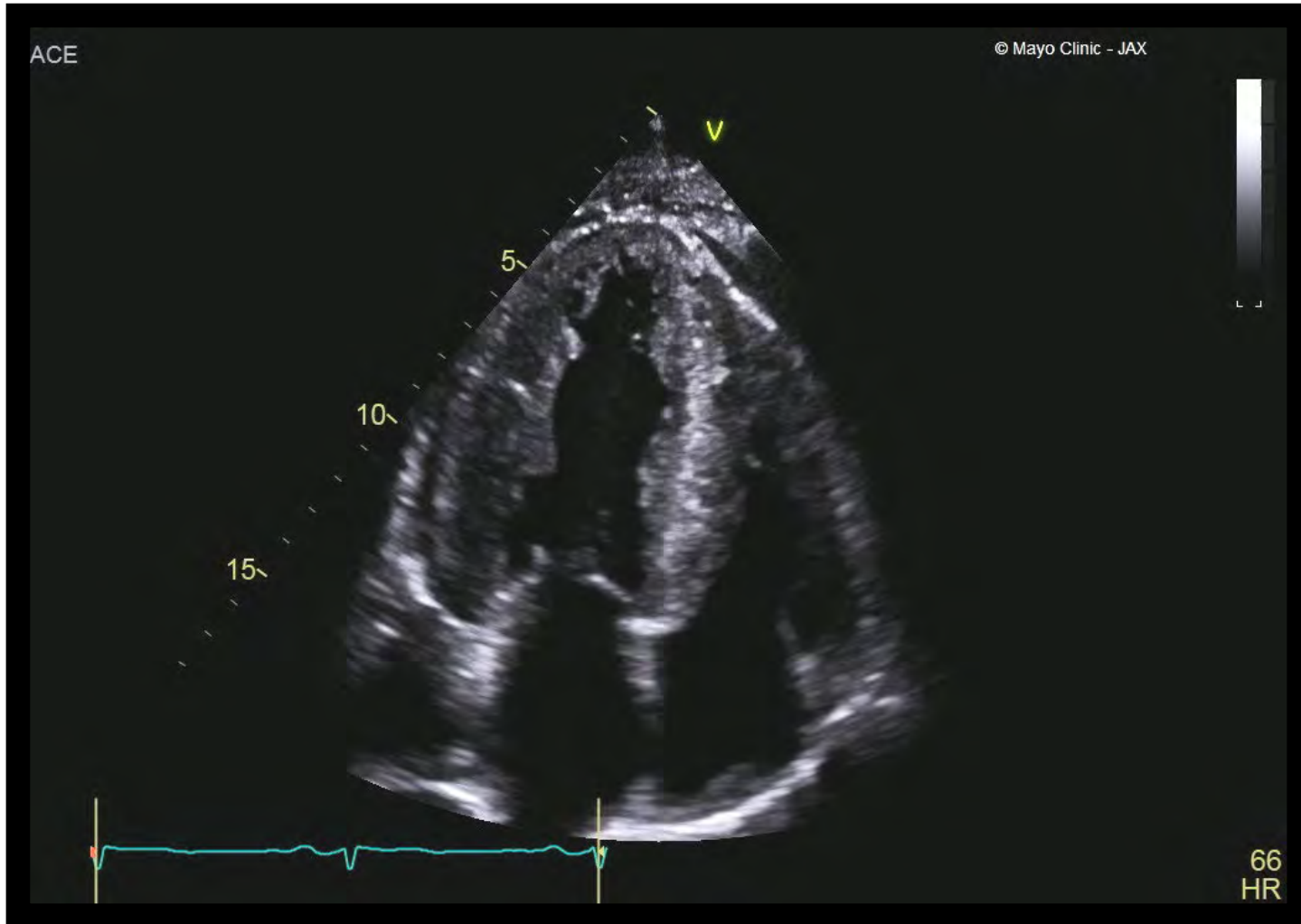


- Heart failure \geq 65 years
- Aortic stenosis in \geq 65 years
- Autonomic dysfunction
- Peripheral polyneuropathy
- Bilateral carpal tunnel syndrome
- Ruptured biceps tendon
- Perioral/periorbital purpura
- Macroglossia
- Low voltage on ECG
- Decreased QRS voltage to mass ratio
- Pseudo Q waves on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





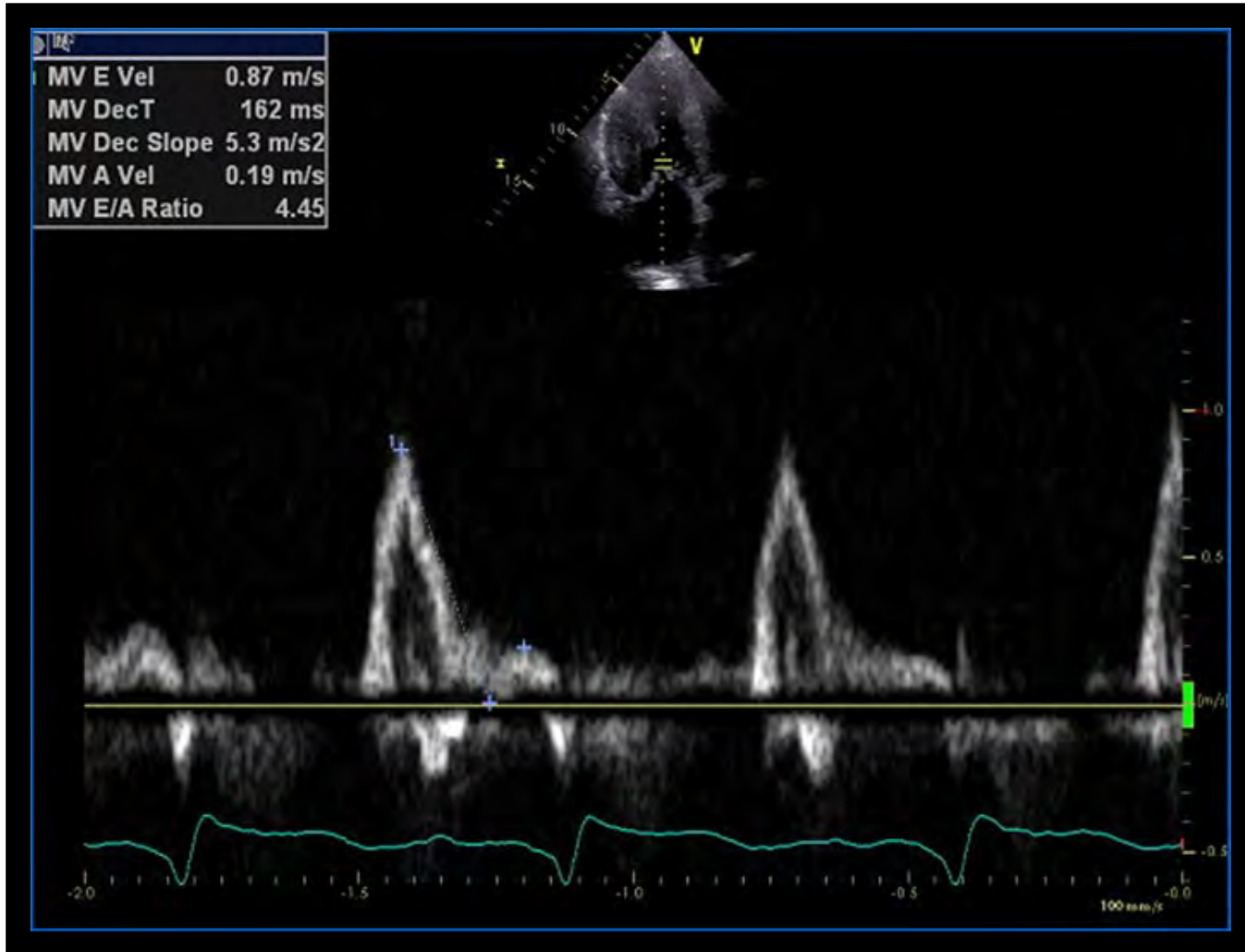
Echocardiographic Features



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

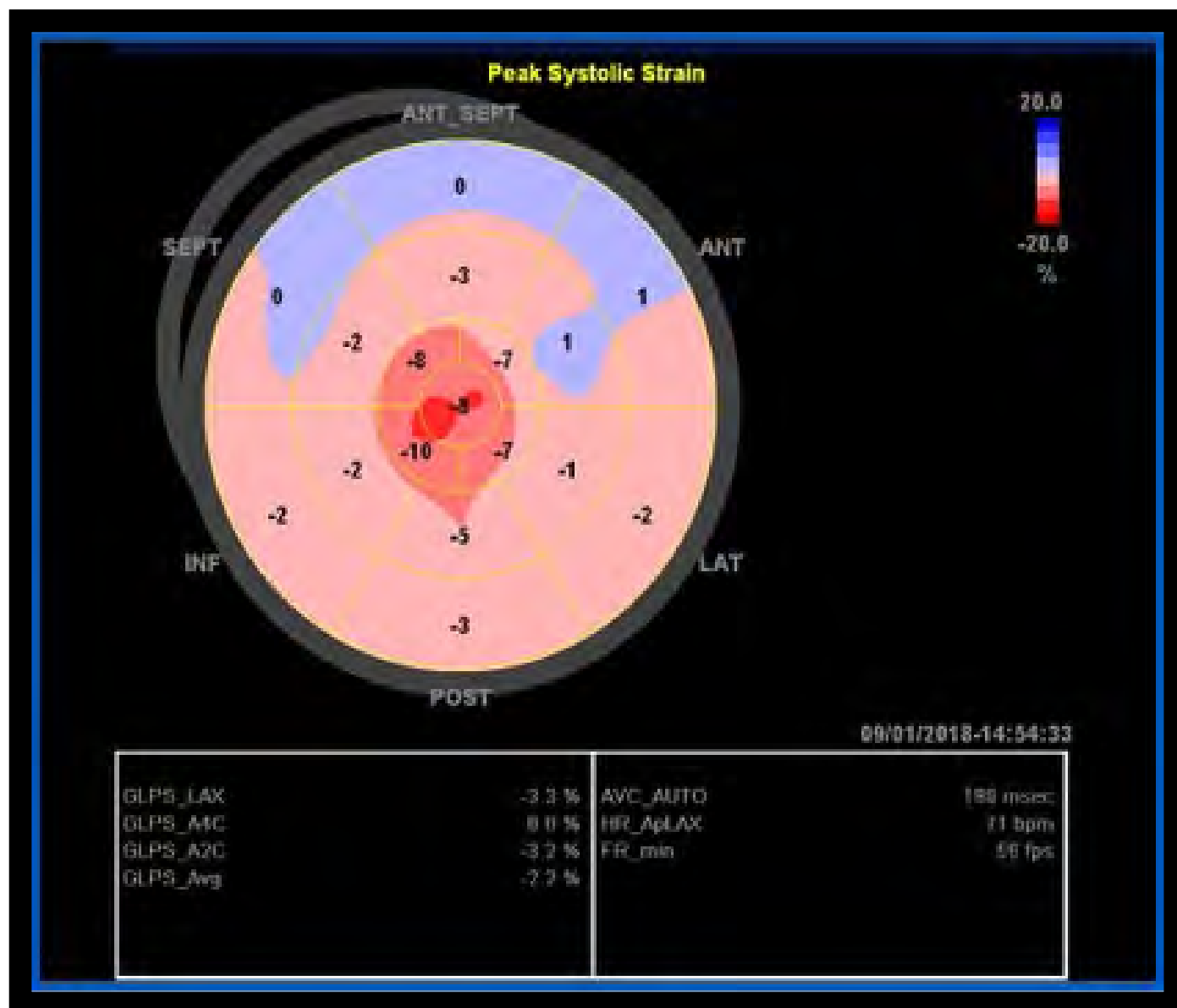


Echocardiographic Features



- 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 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

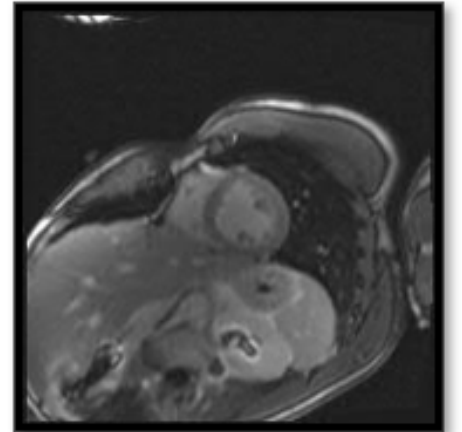
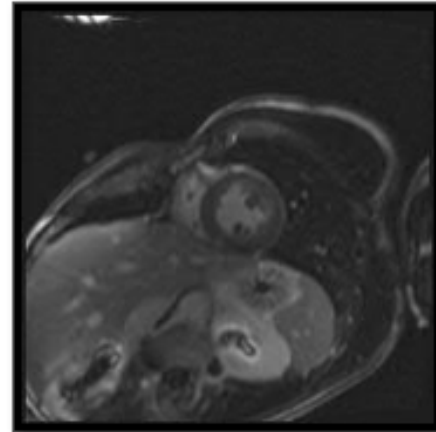
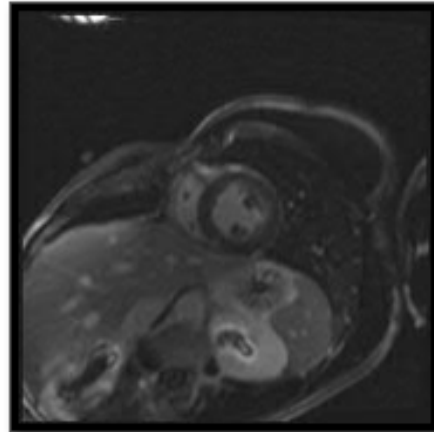
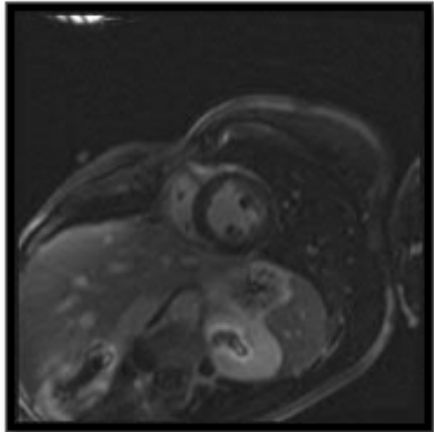
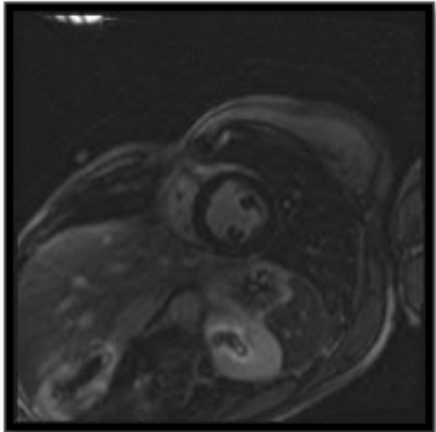
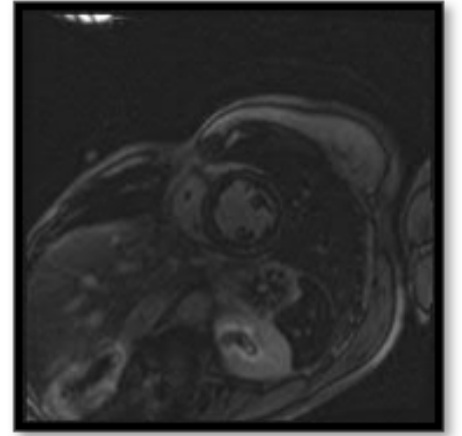
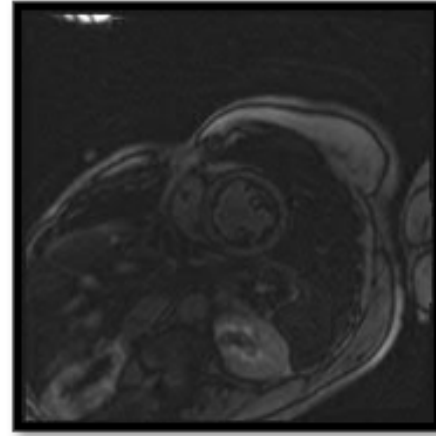
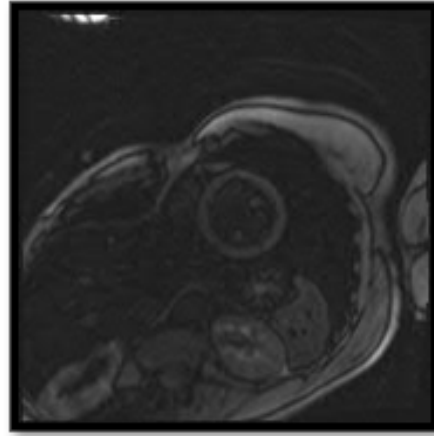
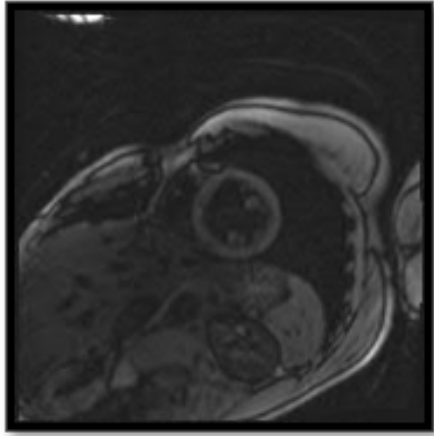
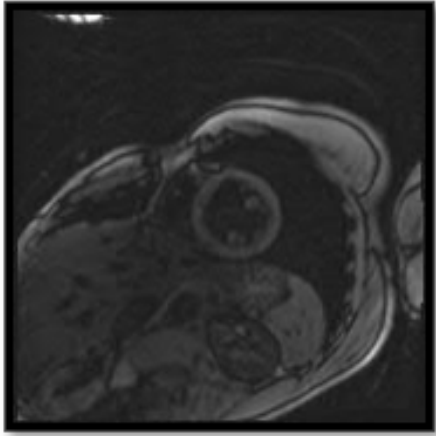
Paolo Milani, MD, Angela Dispenzieri, MD, Christopher G. Scott, MS, Morie A. Gertz, MD, Stefano Perlini, MD, PhD, Roberta Mussinelli, MD, Martha Q. Lacy, MD, Francis K. Buadi, MD, Shaji Kumar, MD, Mathew S. Maurer, MD, Giampaolo Merlini, MD, Suzanne R. Hayman, MD, Nelson Leung, MD, David Dingli, MD, 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



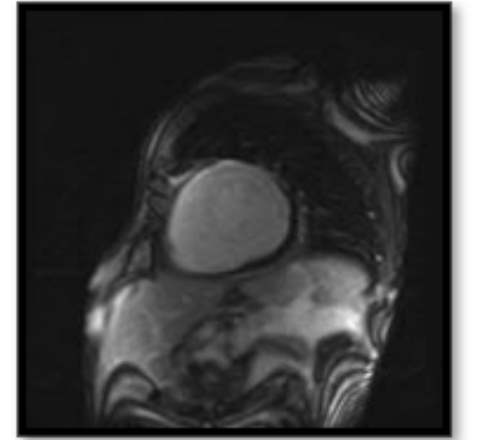
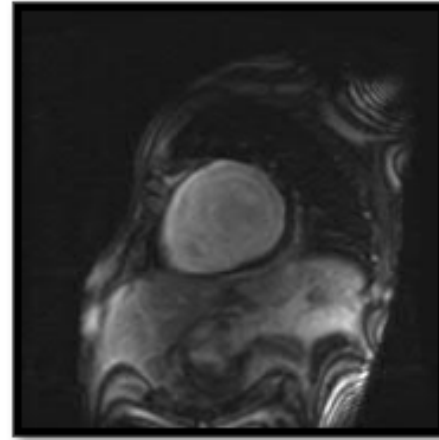
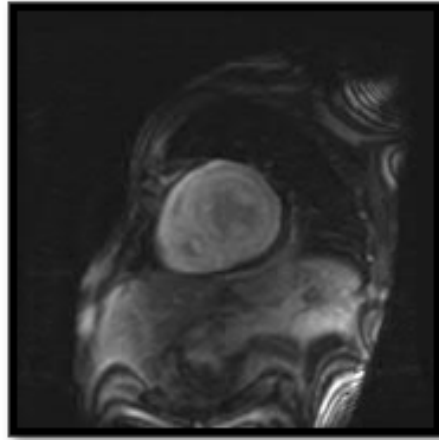
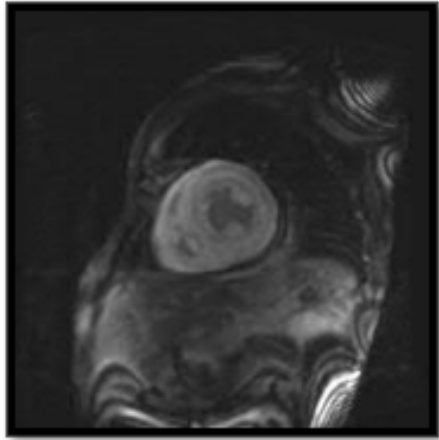
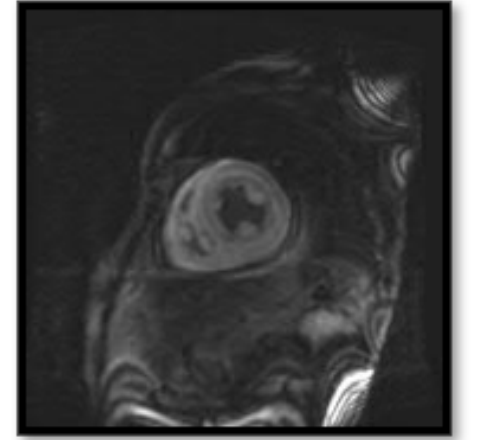
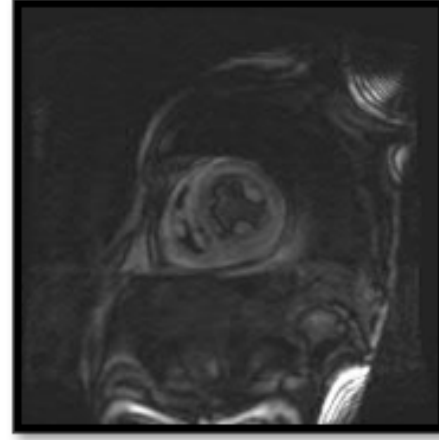
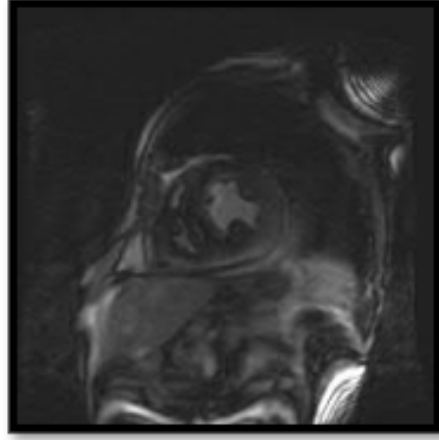
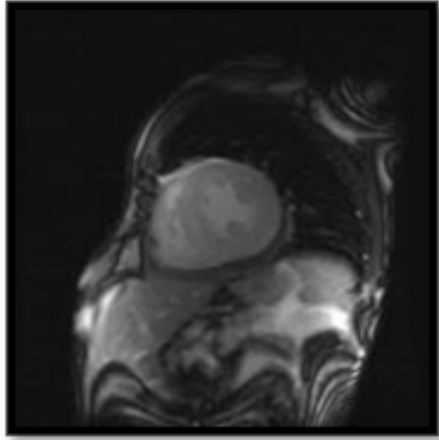
Cardiac Magnetic Resonance



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

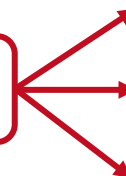


Monoclonal Protein Screen

Serum free light chains

Serum immunofixation
not SPEP alone

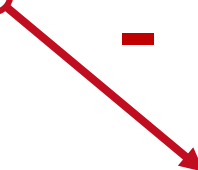
24-hour urine
immunofixation
not UPEP alone



Monoclonal Protein?

+

-



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

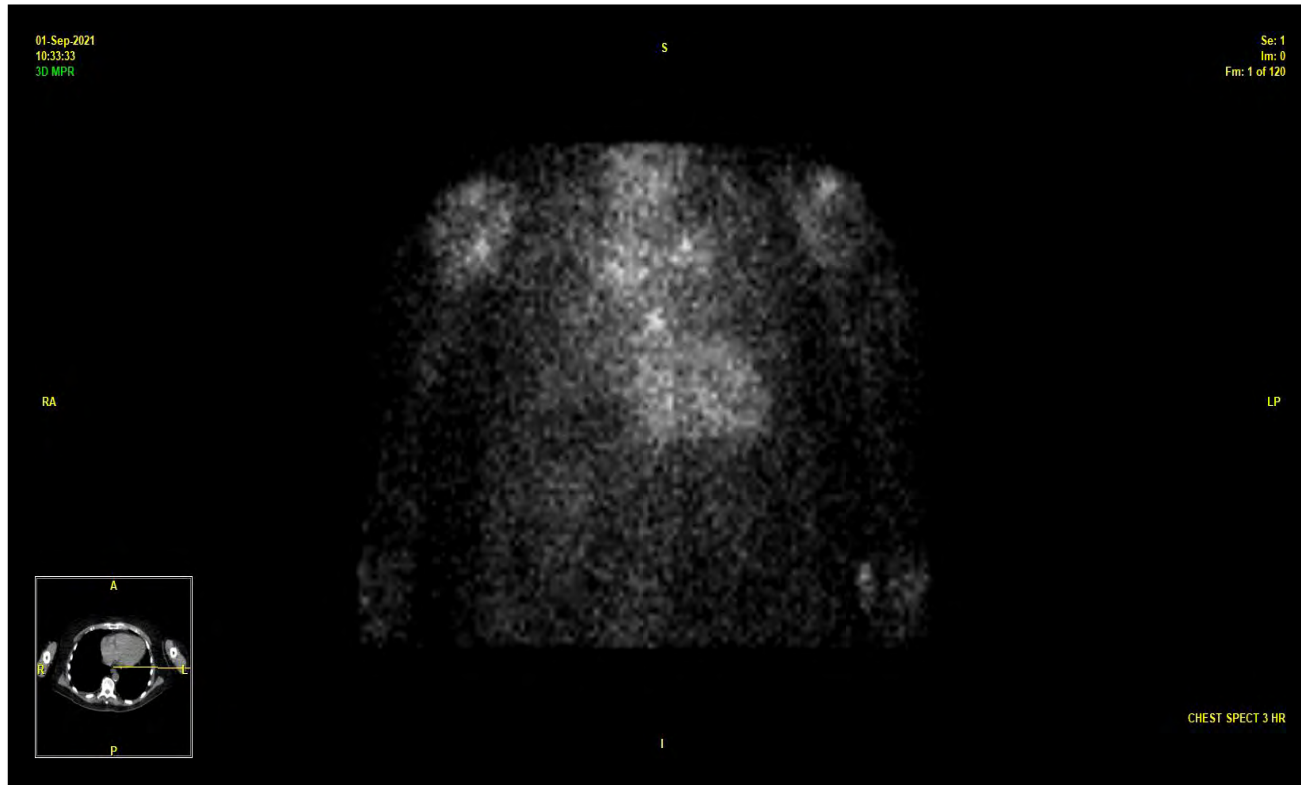
Cardiac scintigraphy



Genetic testing



Cardiac Scintigraphy



- ^{99m}Tc -labeled pyrophosphate (PYP)
- ^{99m}Tc -labeled 3,3-diphosphono-1,2-propanodicarboxylic acid (DPD)
- ^{99m}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?
False positive	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 β 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.
False negative	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 β 2M, β 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

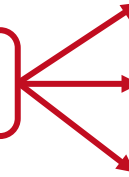


Monoclonal Protein Screen

Serum free light chains

Serum immunofixation
not SPEP alone

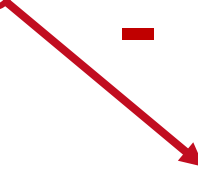
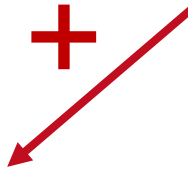
24-hour urine
immunofixation
not UPEP alone



Monoclonal Protein?

+

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

Cardiac scintigraphy



Genetic testing

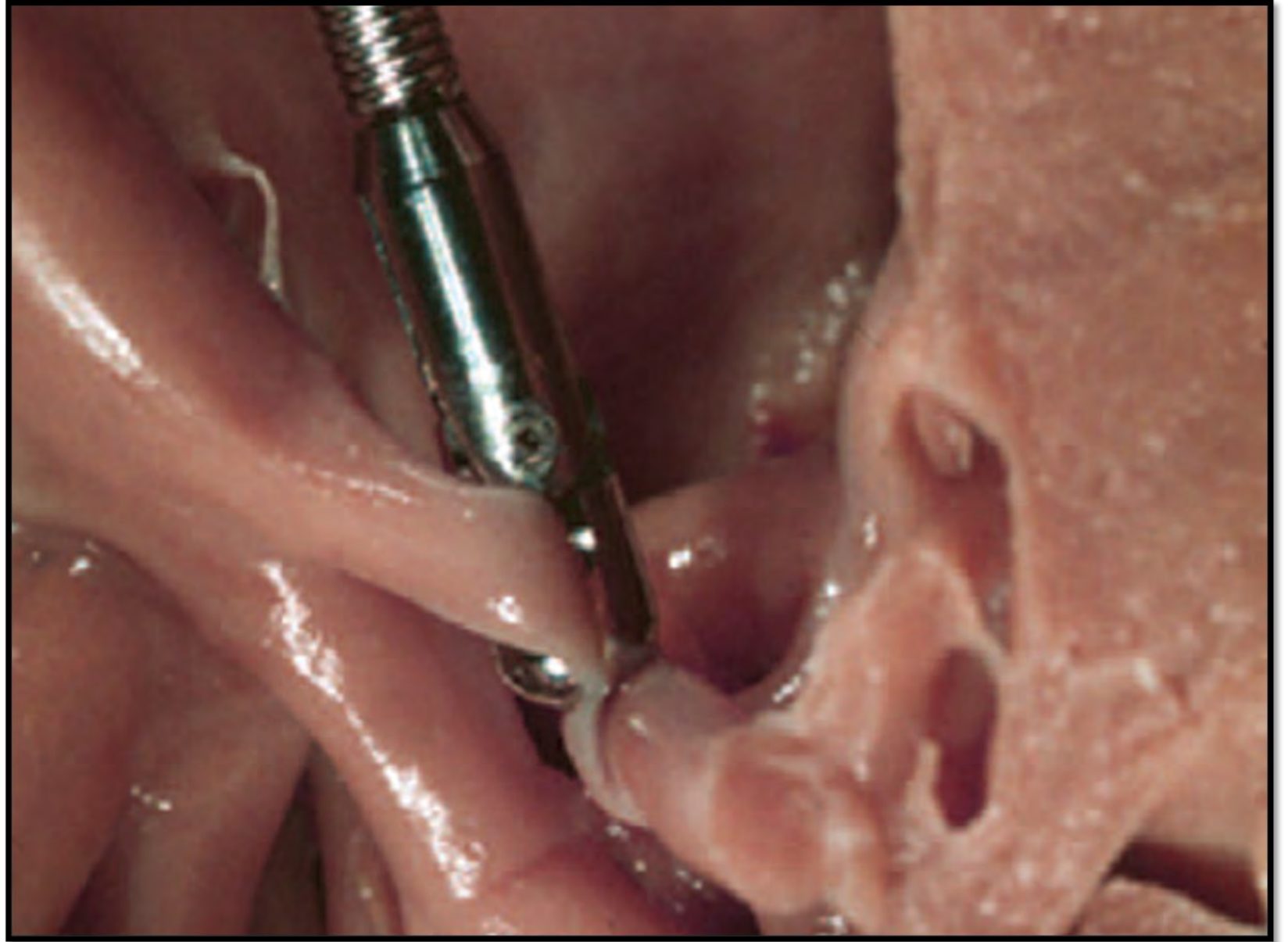


M — Must

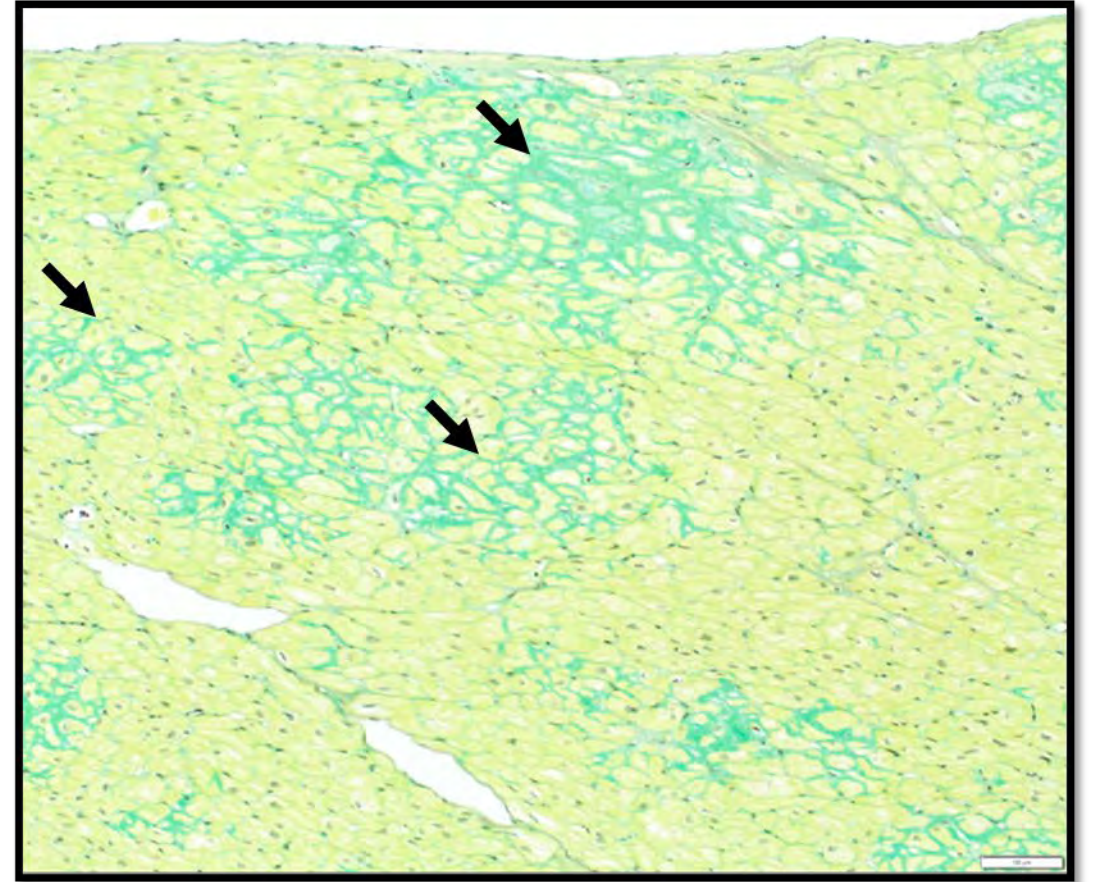
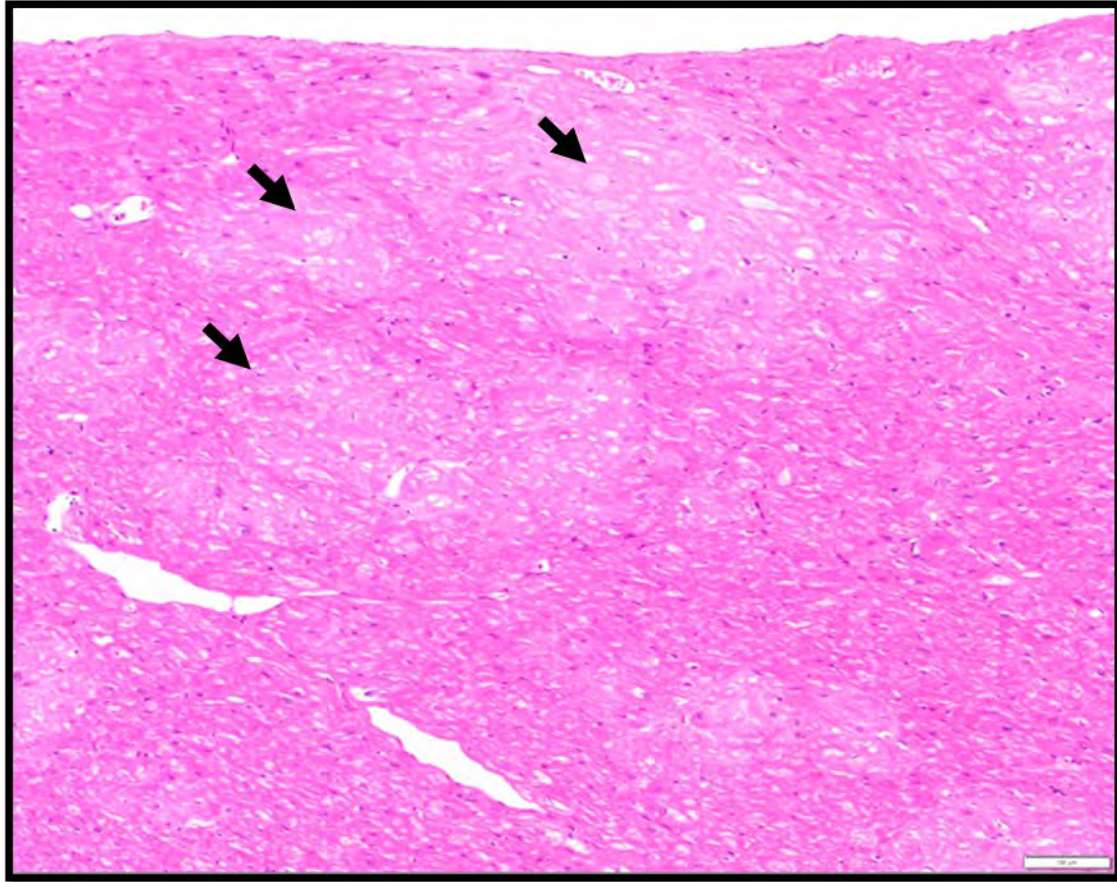
G — Go

U — Under

S — Skin

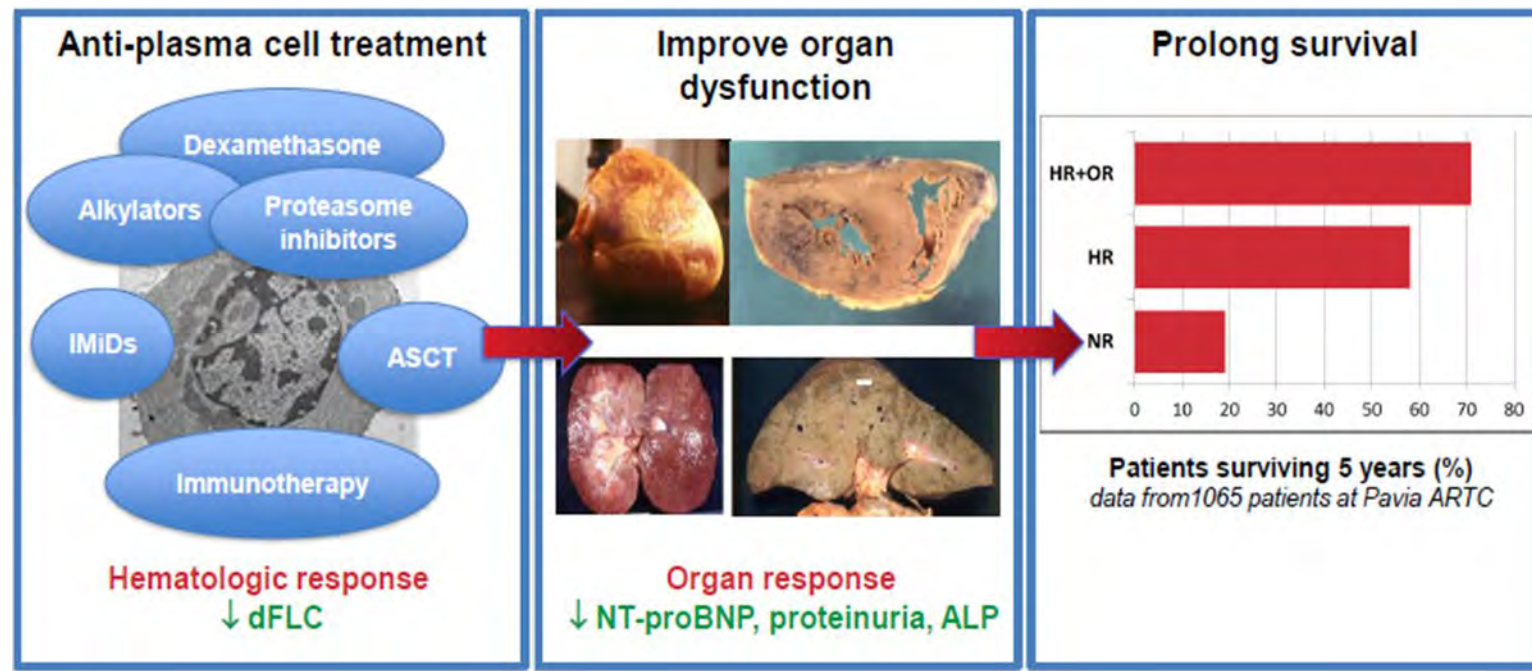


Acronym courtesy of Dr. Dan Judge, shared by Dr. Martha Grogan, Mayo Clinic Rochester



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

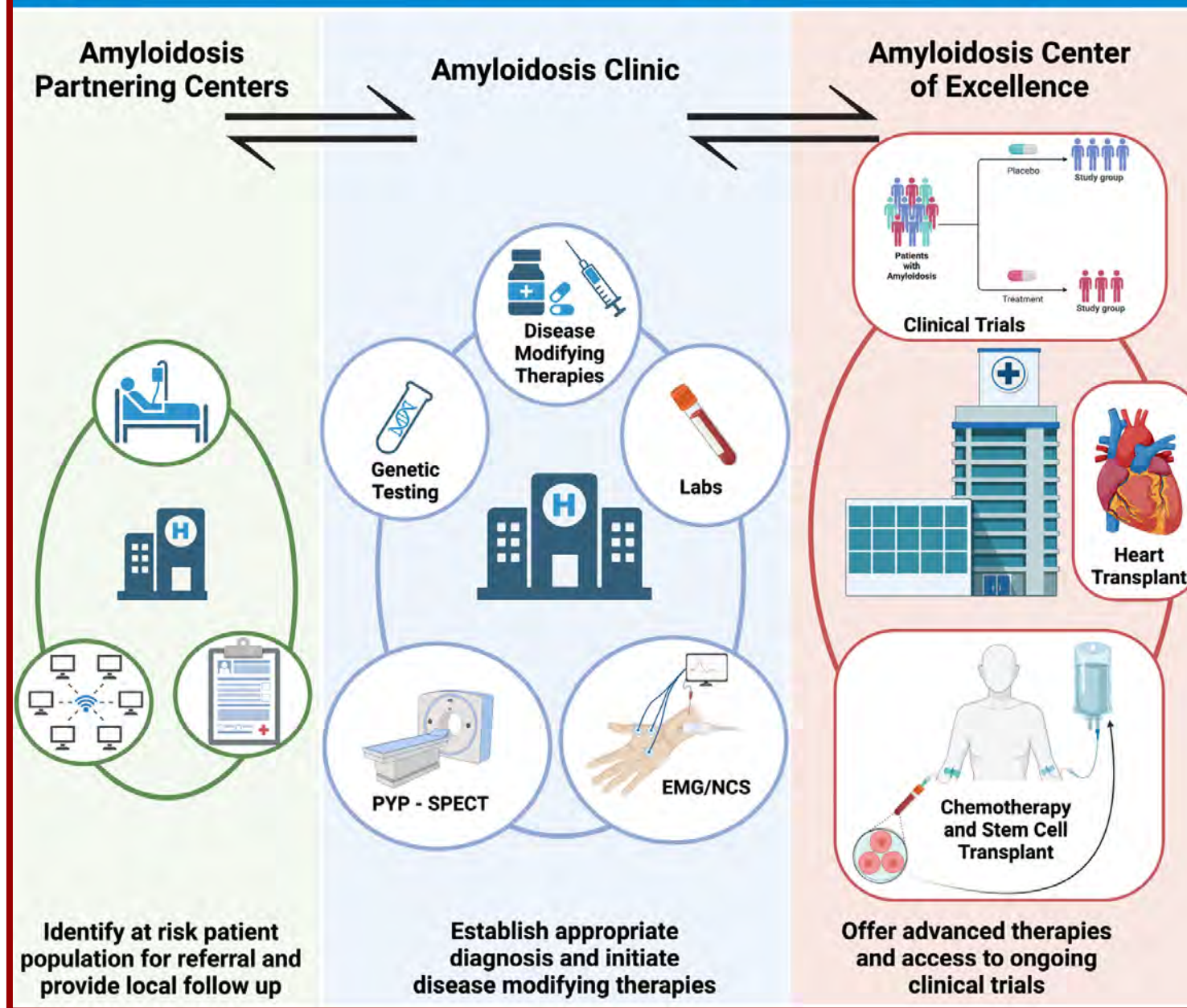




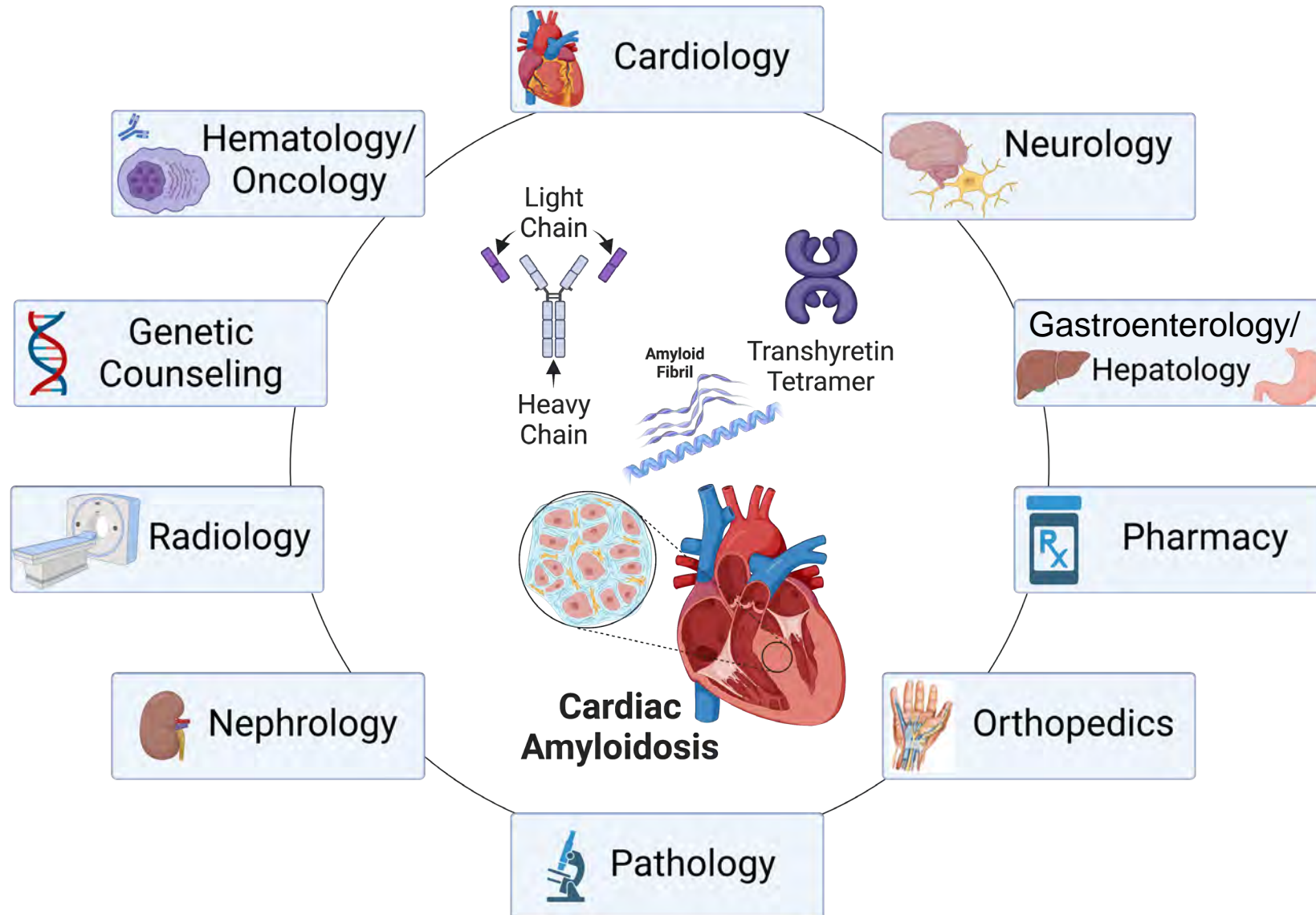
A Multidisciplinary Approach is Key



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**

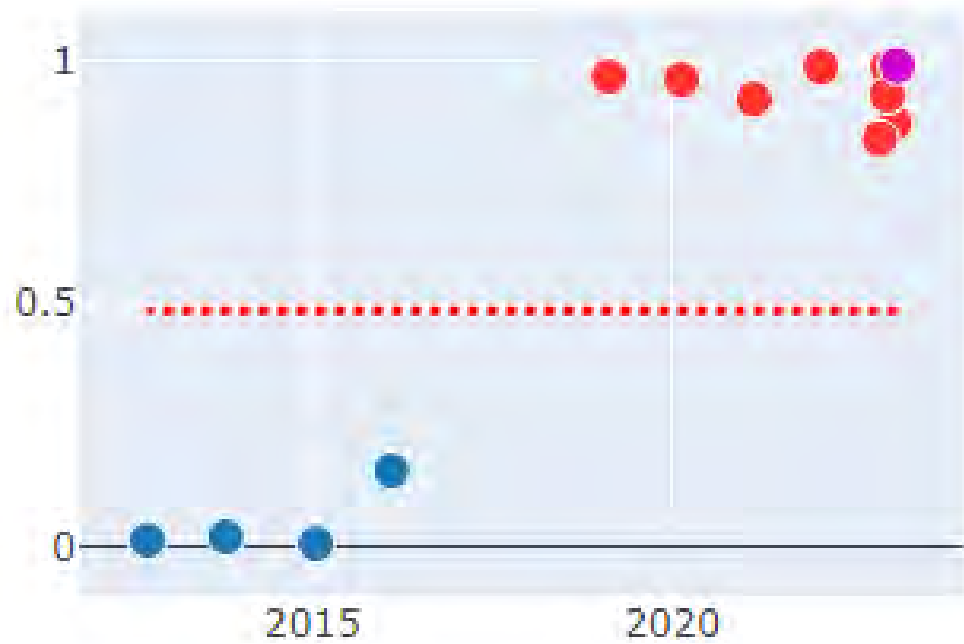
Complex Diagnosis

**Multi-Organ
Involvement &
Complex Therapies**



Artificial Intelligence

Probability of Amyloid



 AI Dashboard

[Show images for ECG 12 Lead](#)



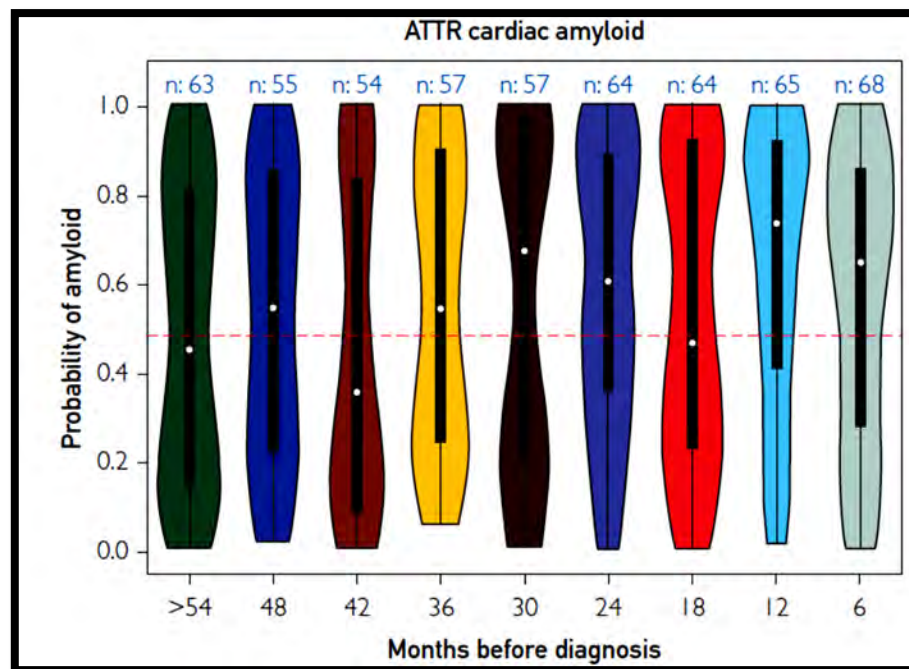
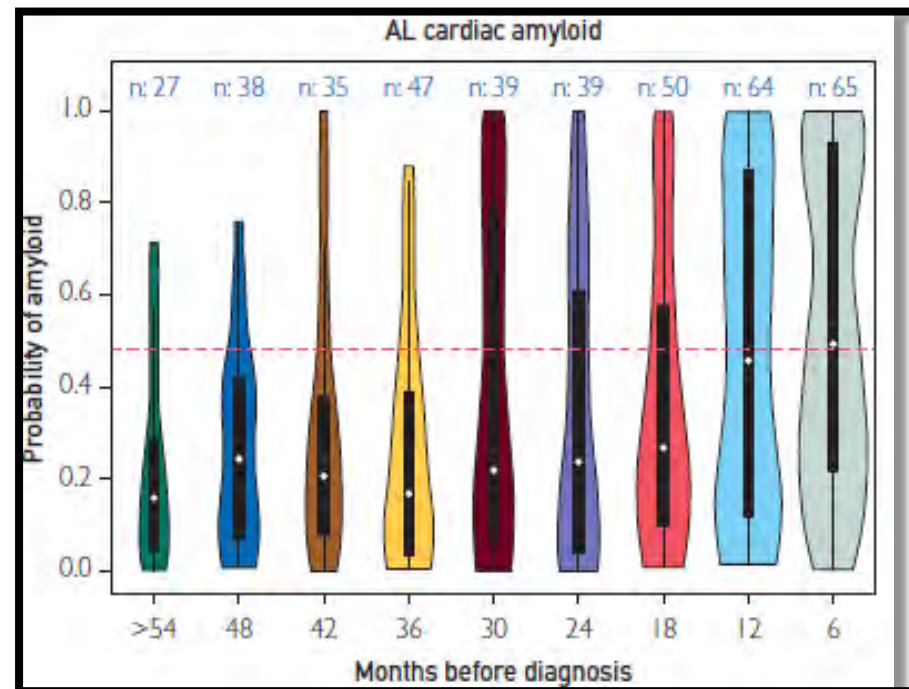
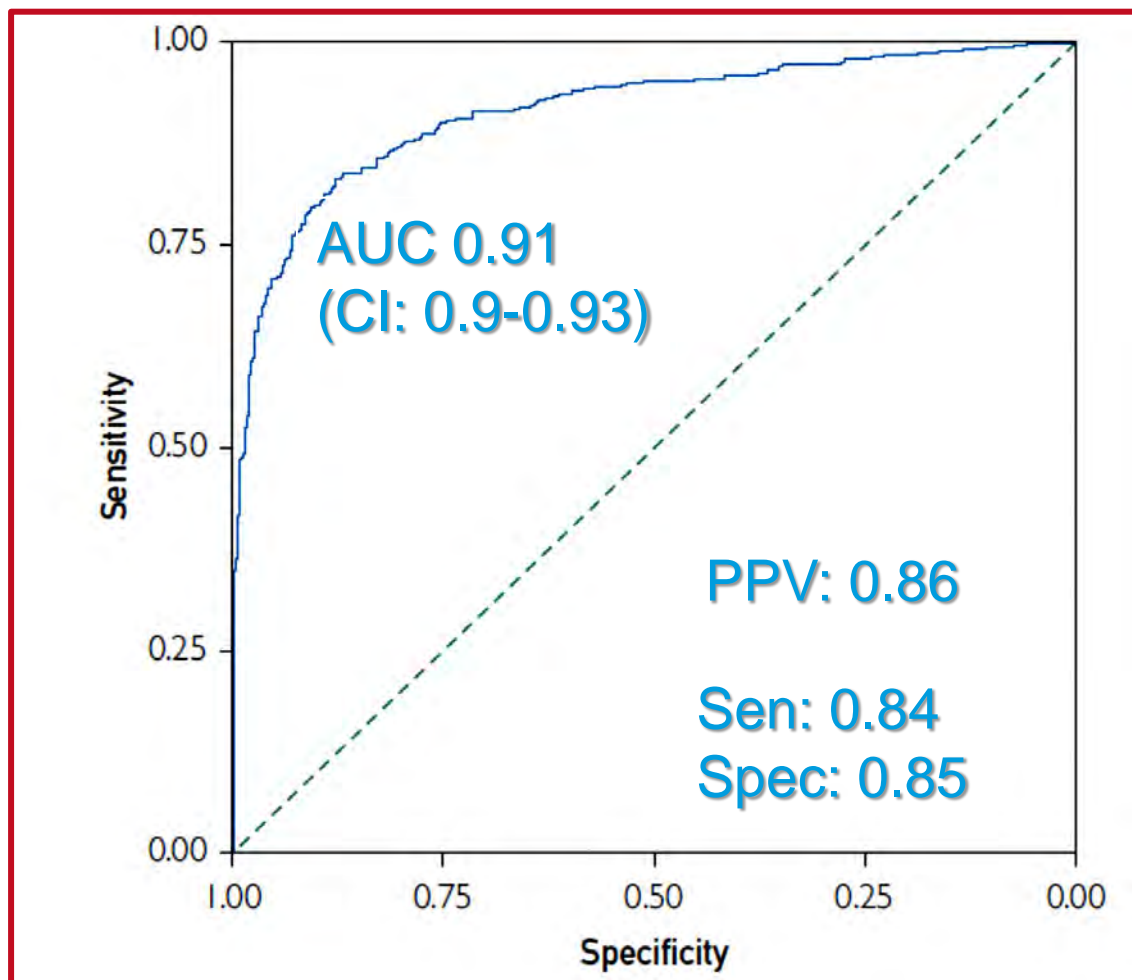


Artificial Intelligence—Enhanced Electrocardiogram for the Early Detection of Cardiac Amyloidosis

Martha Grogan, MD; Francisco Lopez-Jimenez, MD; Michal Cohen-Shelly, BSc;
Angela Dispenzieri, MD; Zachi 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**





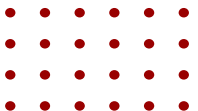
Strengthening Patient Advocacy





Summary & Key Takeaways

- Suspect amyloid: LV wall thickness ≥ 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

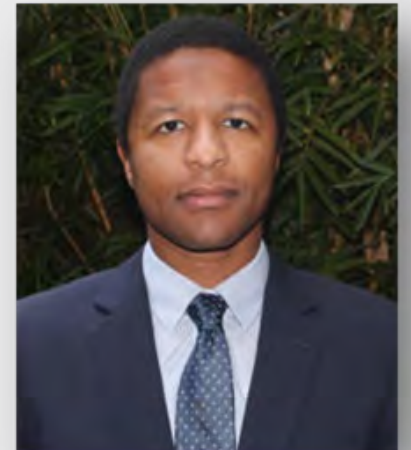
Assistant Professor of Medicine

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.

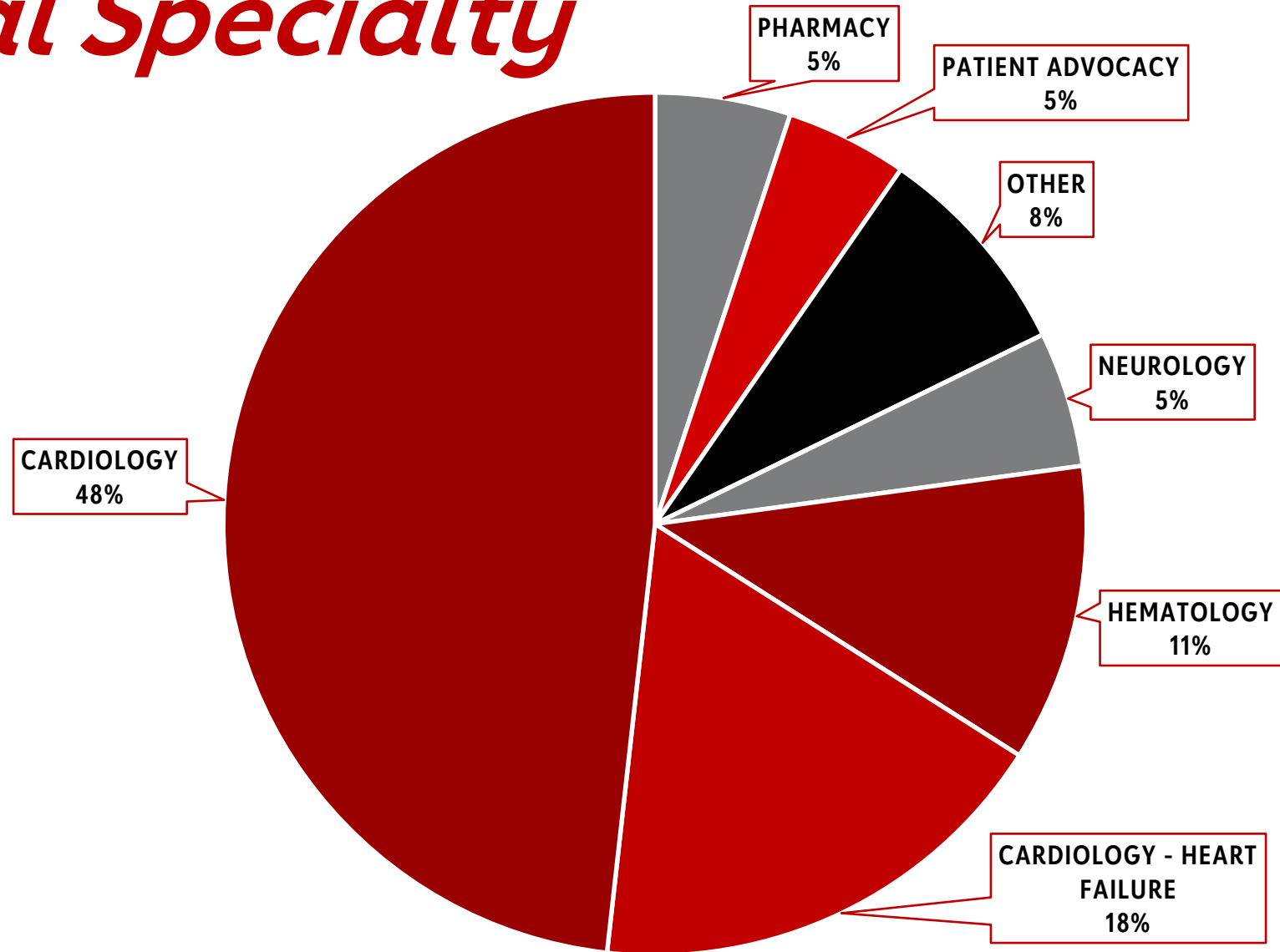


Forum Attendee Metrics



Forum Attendance Metrics:

Medical Specialty



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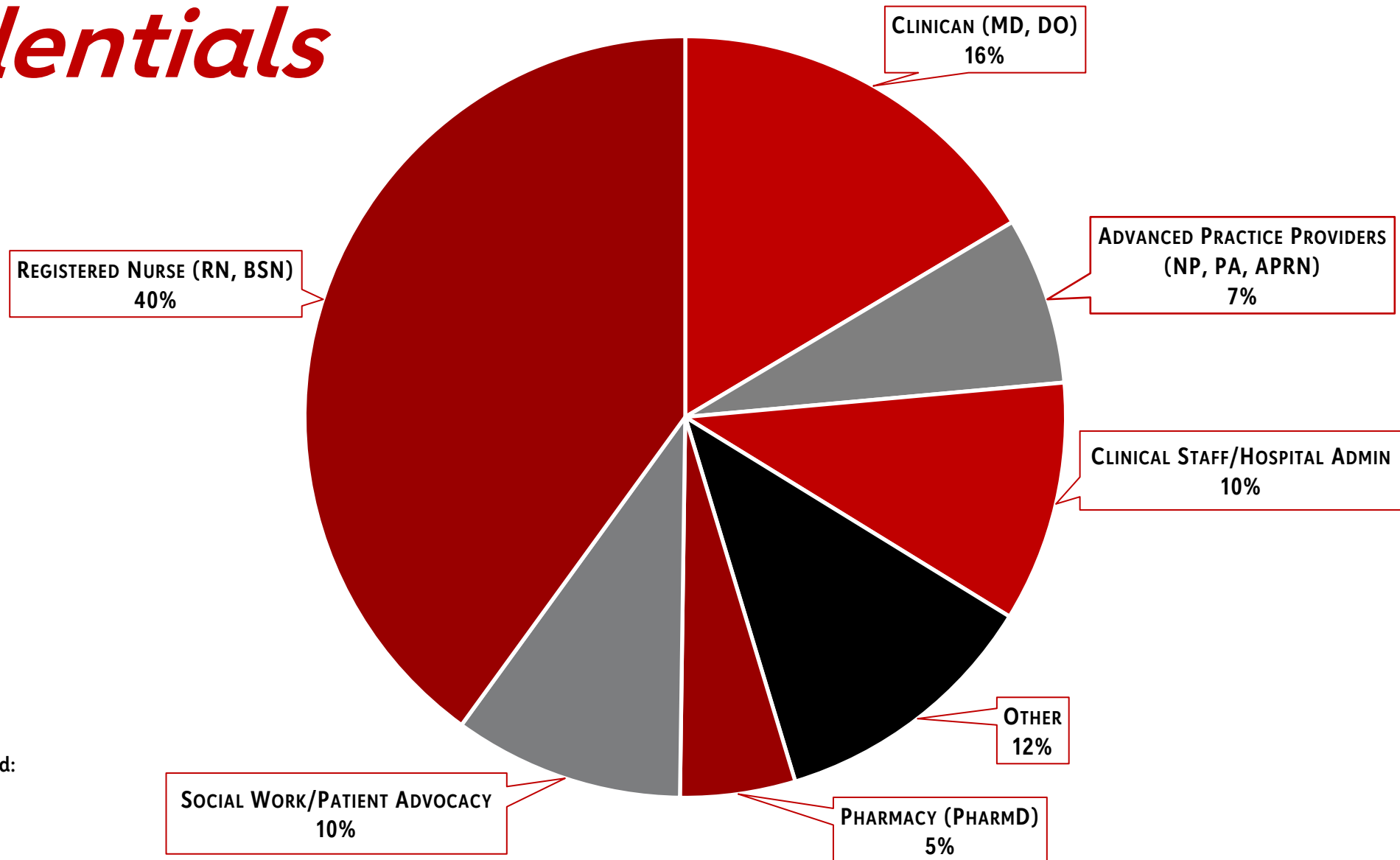
Other specialties reported:

Critical Care
Gastroenterology
General Practice
Internal Medicine
Nephrology



Forum Attendance Metrics:

Credentials



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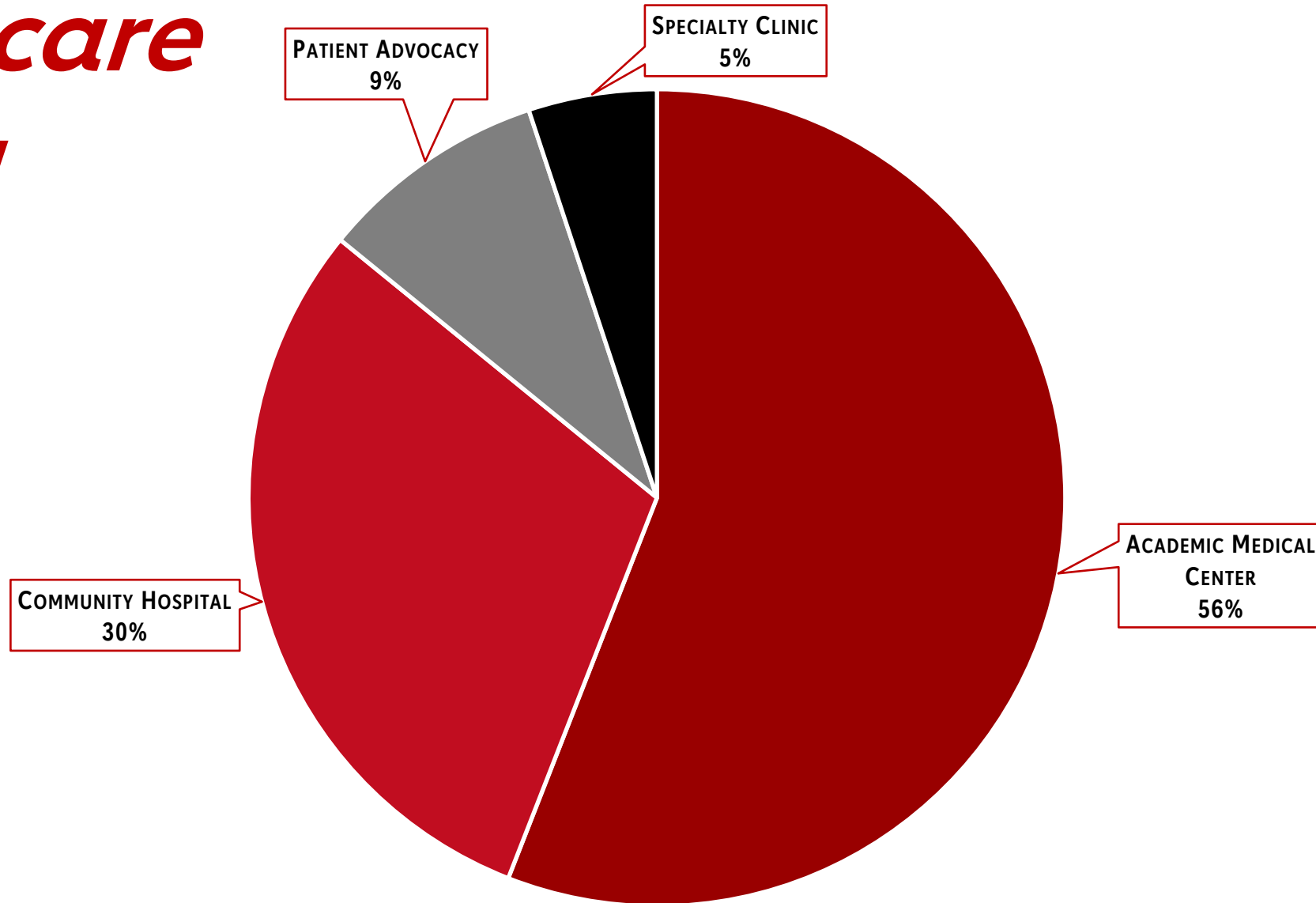
Other credentials reported:

PhD Researchers
Students/ Trainees
Patients
Industry Partners



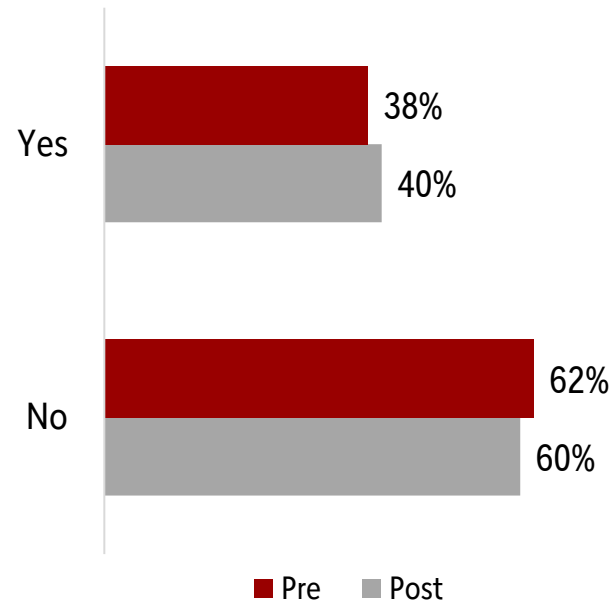
Forum Attendance Metrics:

Healthcare Setting

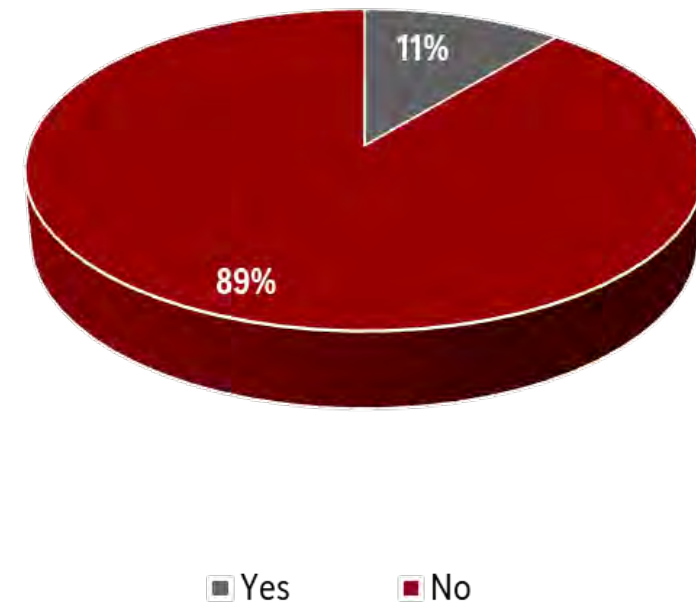


Institutional Characteristics

Does respondent's organization have an Amyloid Center?



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





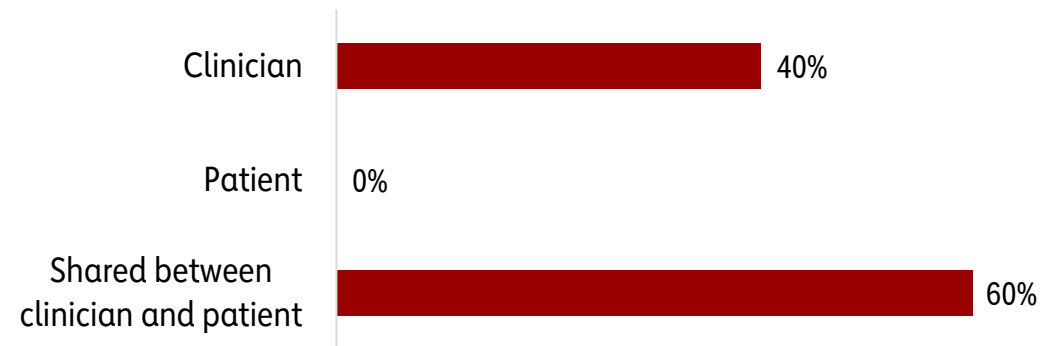
Disease Management



Shared Decision-Making and Patient Preparedness

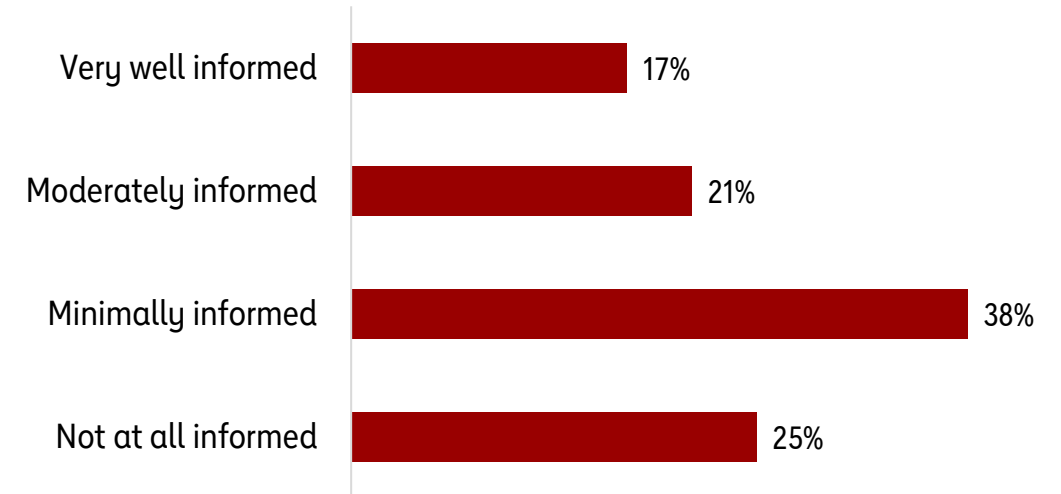
PRE

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



PRE

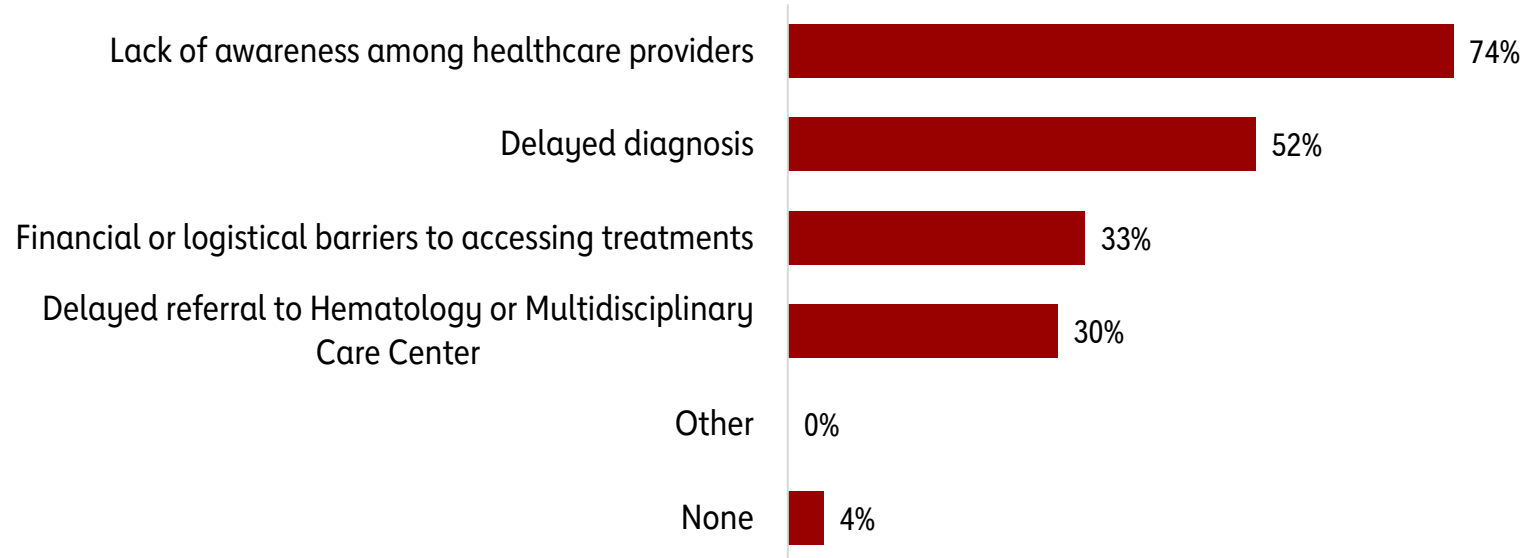
On average, how well informed are patients about their AL-Amyloidosis treatment options before discussing them with their clinician?



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.

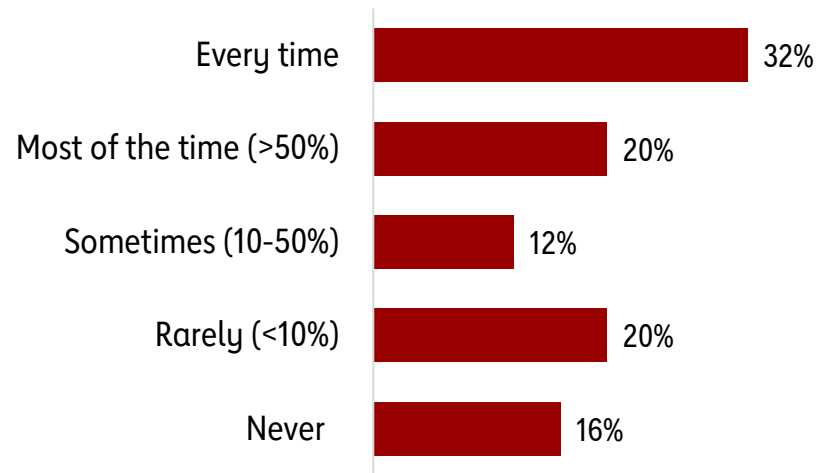
It's time to strengthen recognition and remove obstacles to timely care!



Evolving Referral Practices

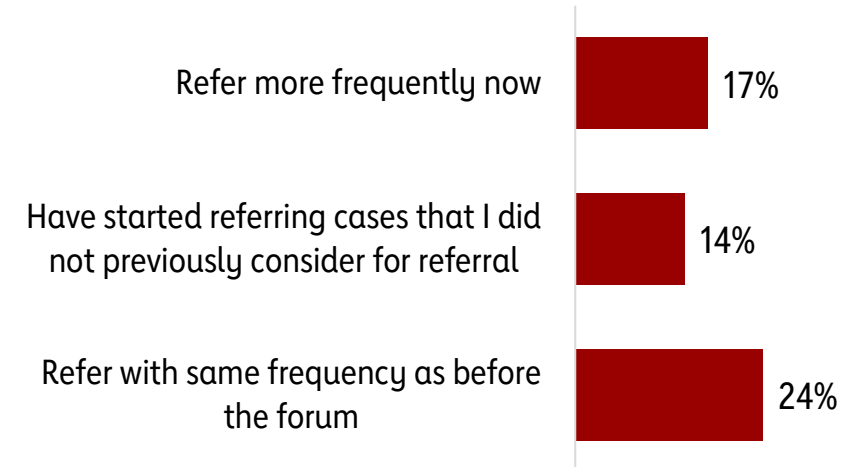
PRE

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.

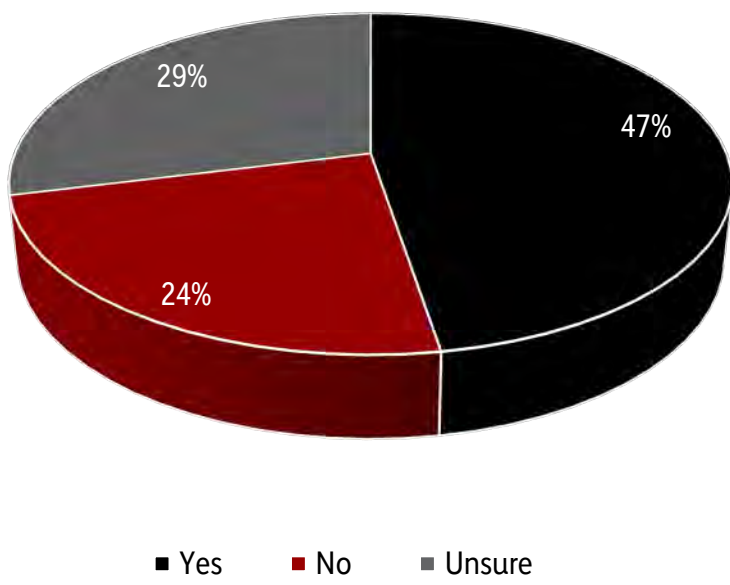




Institutional Protocols

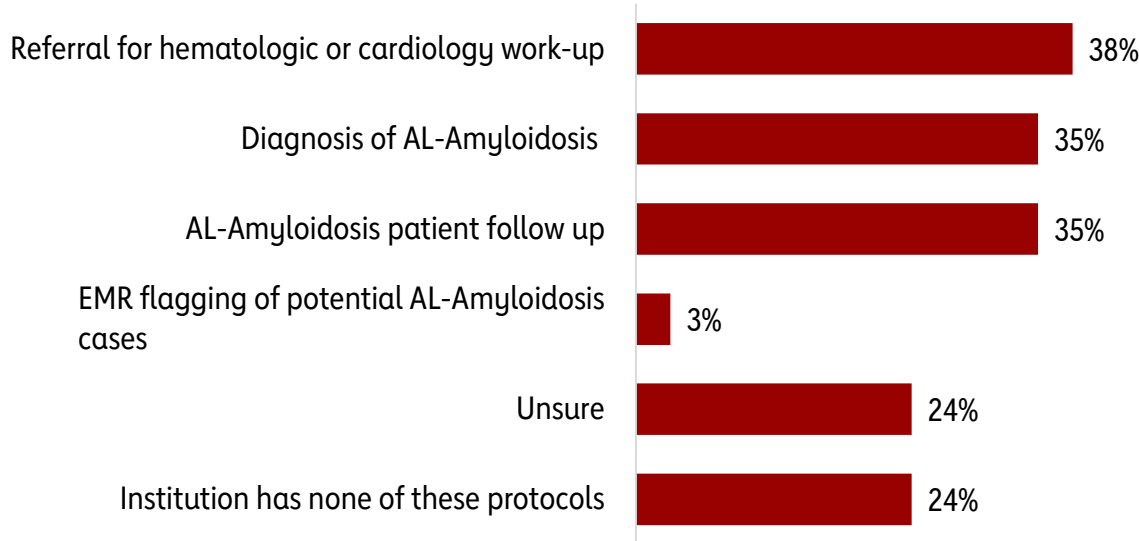
PRE

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



PRE

Respondent's institution has these protocols.

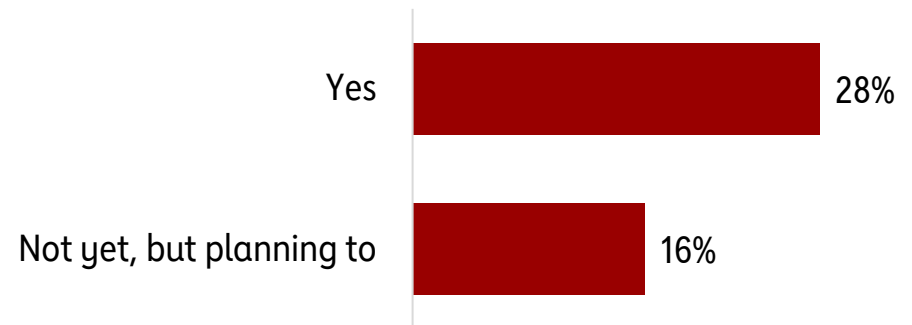


Turning Awareness Into Action: Institutional Protocols in Motion

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

POST

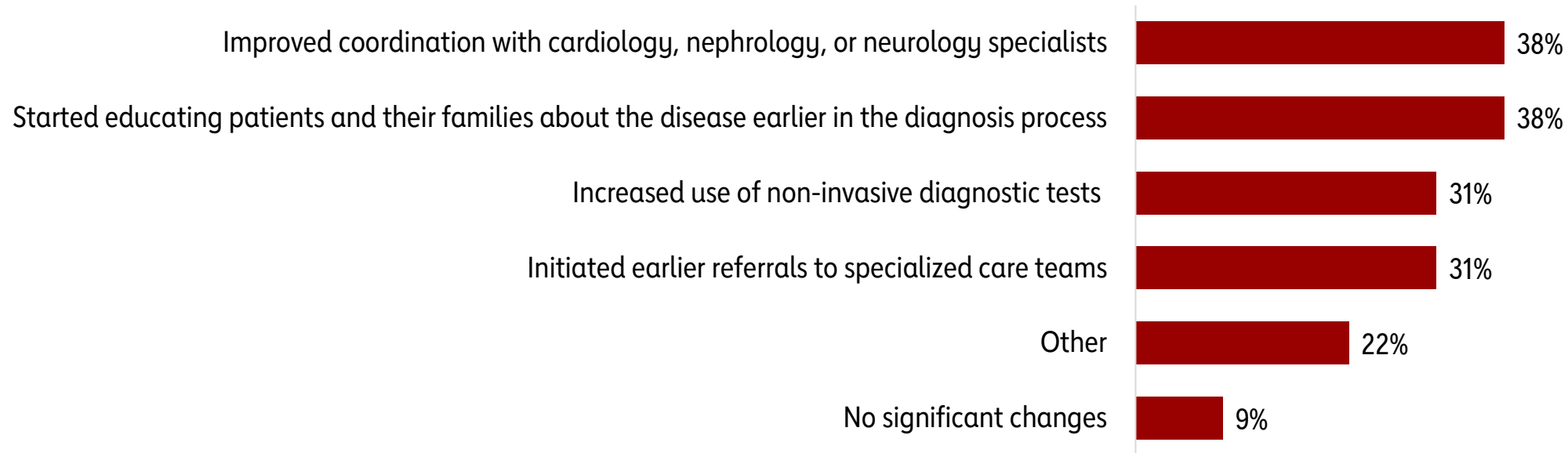
Since attending the forum, have you implemented or considered implementing any new diagnostic protocols or referral pathways for AL-Amyloidosis patients at your institution?



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?

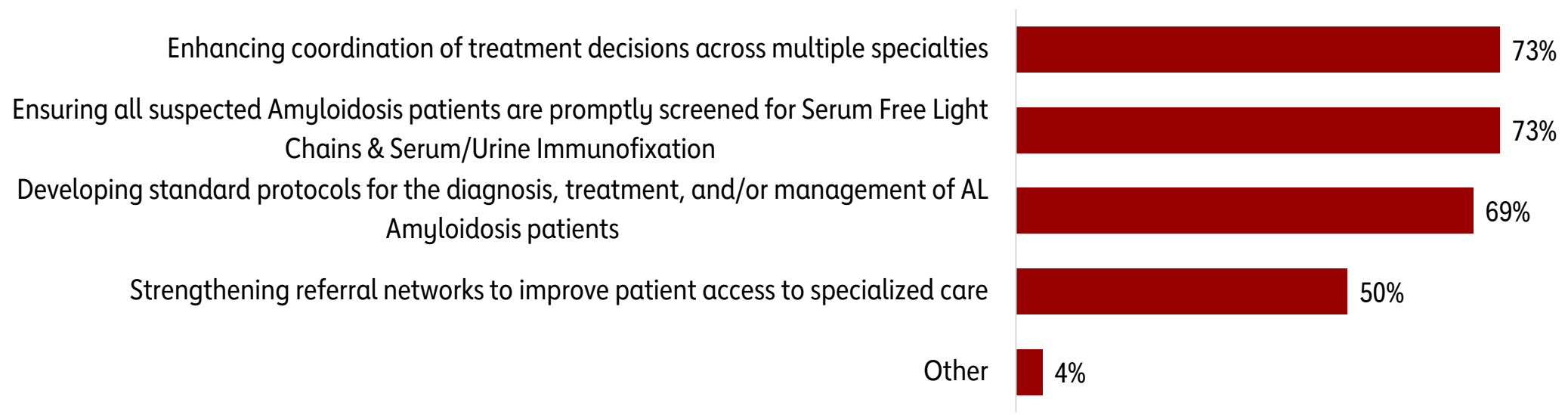




Turning Awareness Into Action: Institutional Protocols in Motion

POST

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

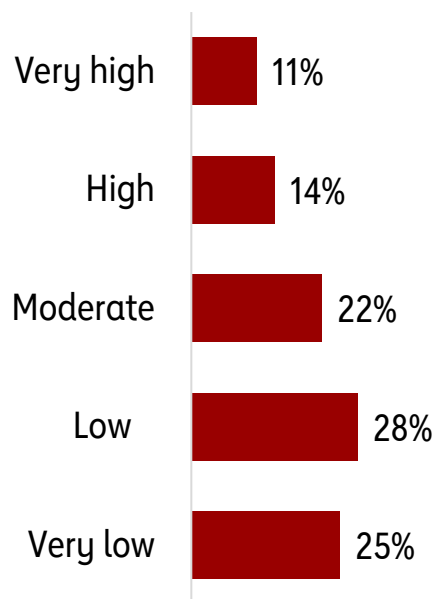


Disease Confidence & Education Impact

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.

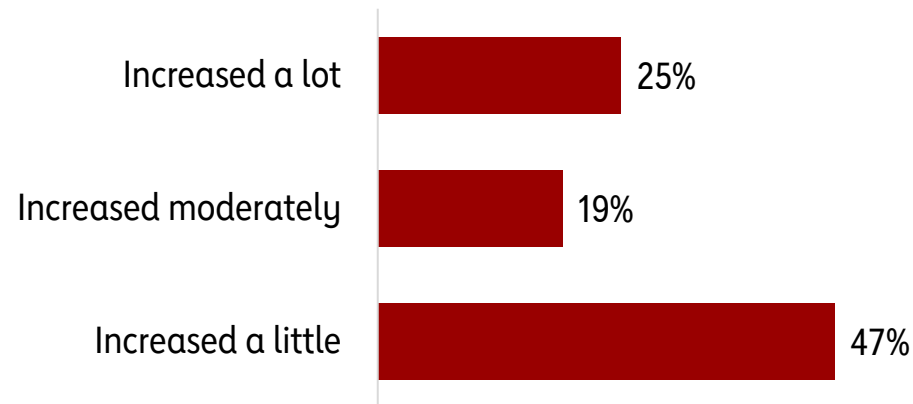
This underscores the need for targeted **education** and **support**.



Confidence Boost: What Providers Gained from the Forum

POST

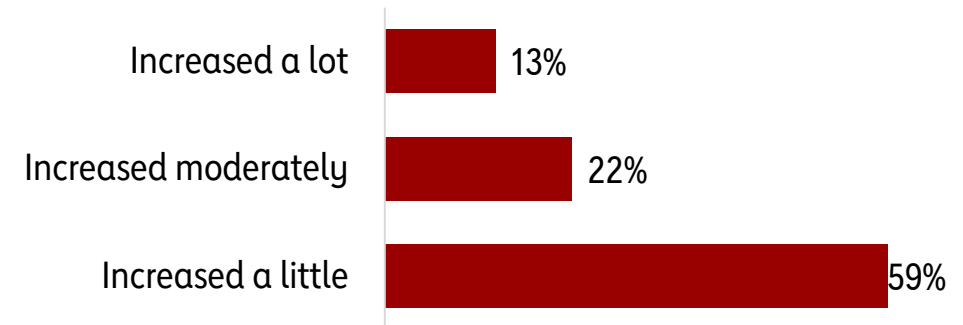
Since attending the AL-Amyloidosis National Patient to Provider Connection Forum, to what extent has your confidence in diagnosing AL-Amyloidosis changed?



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?

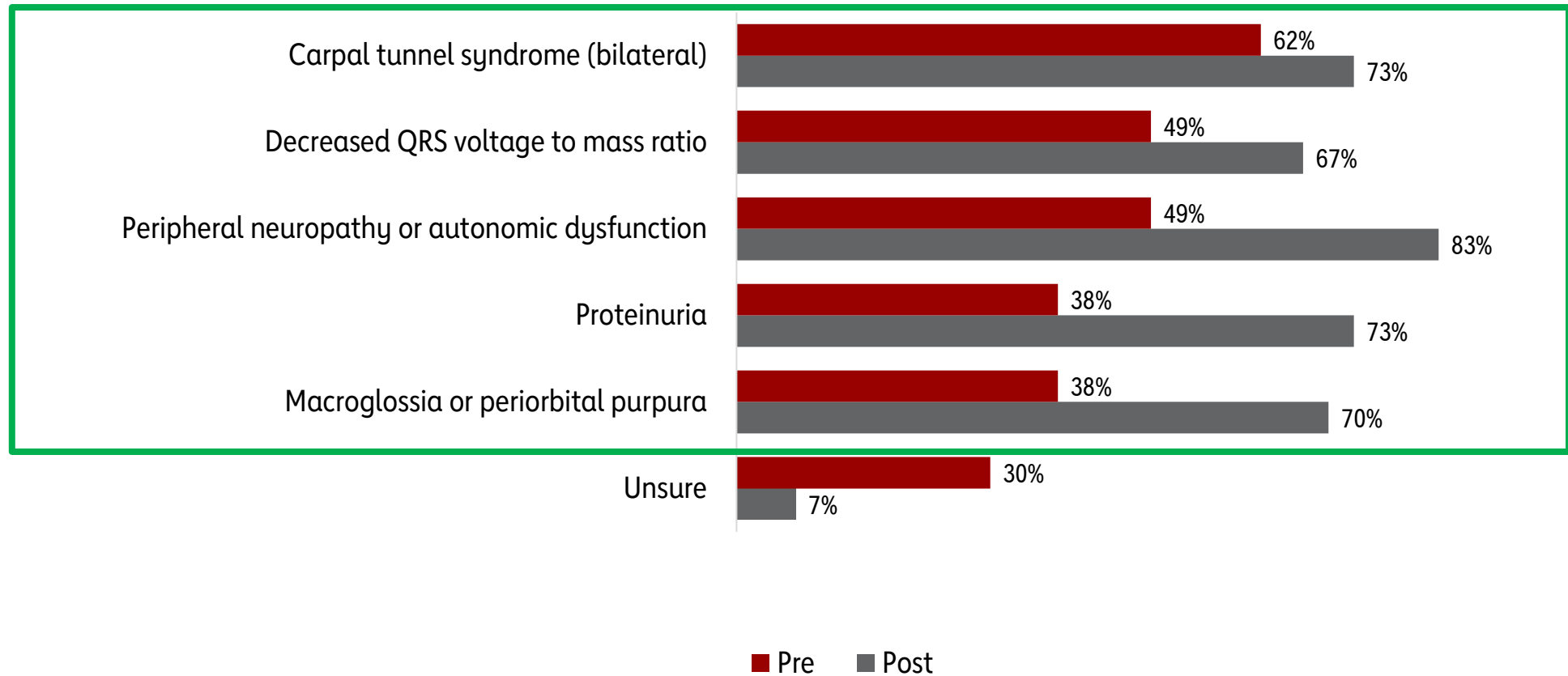


Fewer respondents reported their confidence in interpreting diagnostic tests increased “a lot” or “moderately” (35%) compared to increases in confidence in diagnosing (44%).



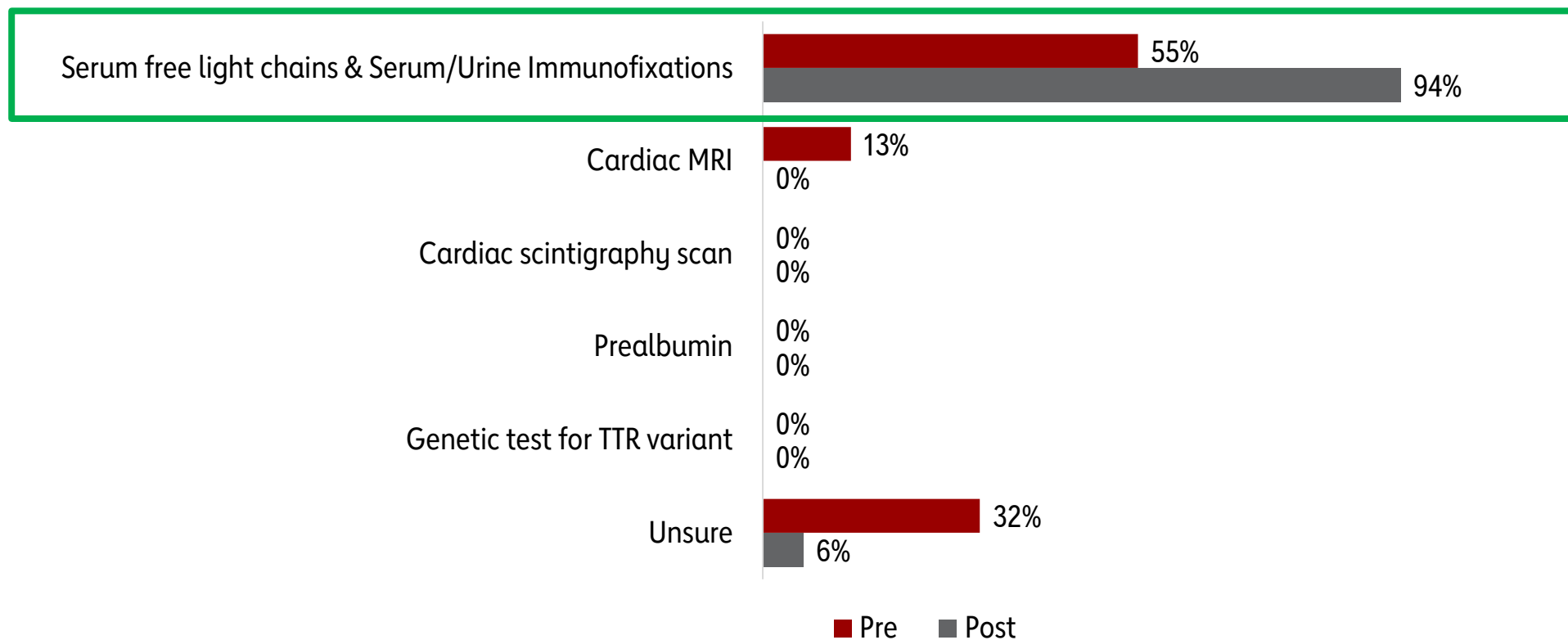
Pre vs Post: Respondents' Knowledge

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?



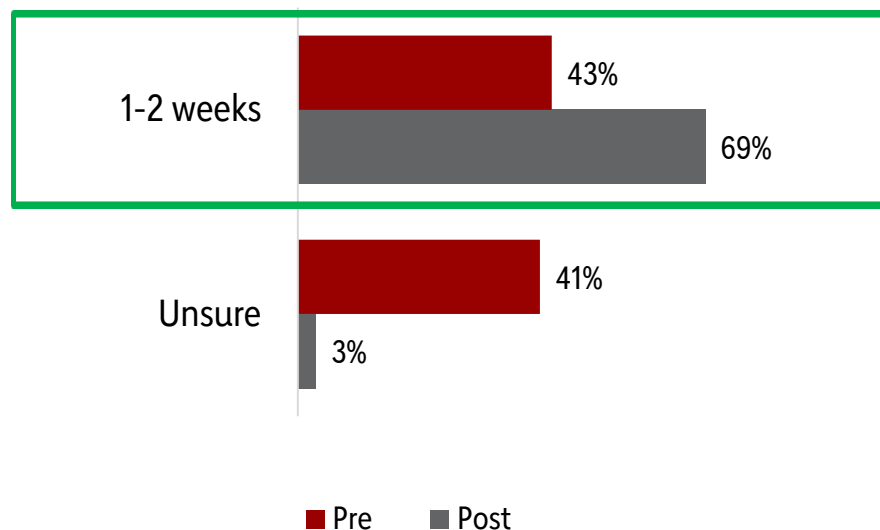
Nearly all post-forum respondents selected the correct initial test compared to just over half of pre-forum respondents.



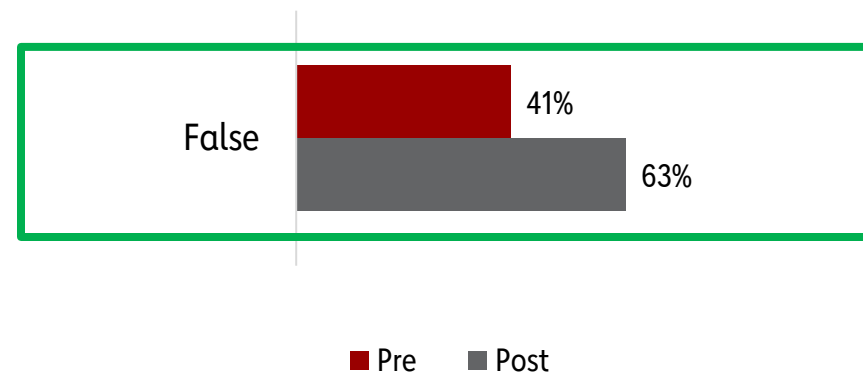
Pre vs Post: Respondents' Knowledge



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



AL-Amyloidosis can be diagnosed without a biopsy.





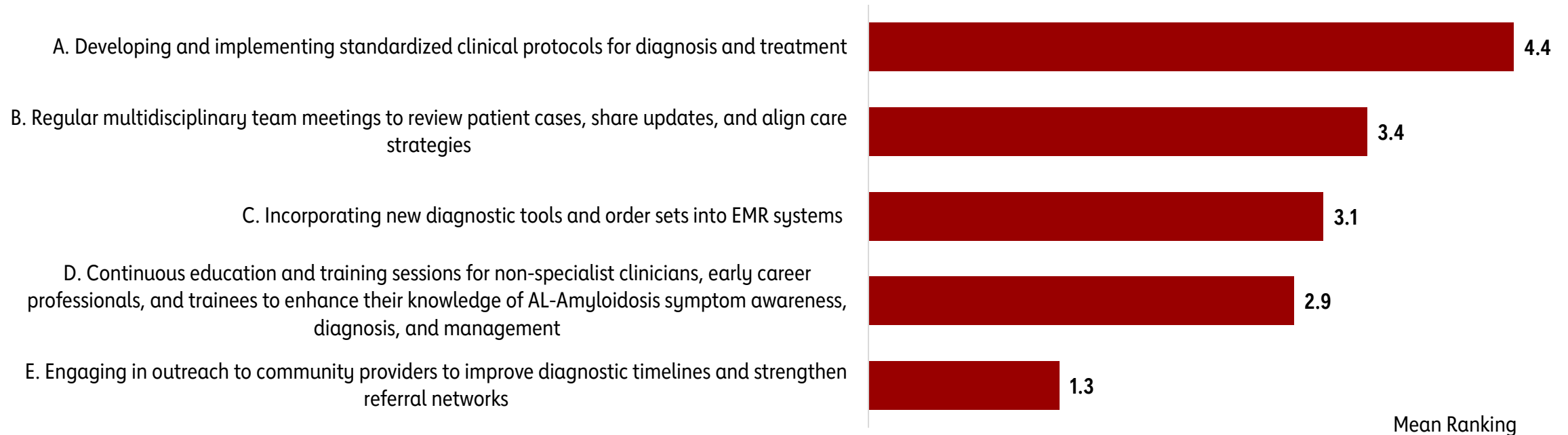
Respondents' Perspectives



Respondents' Perspectives

POST

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



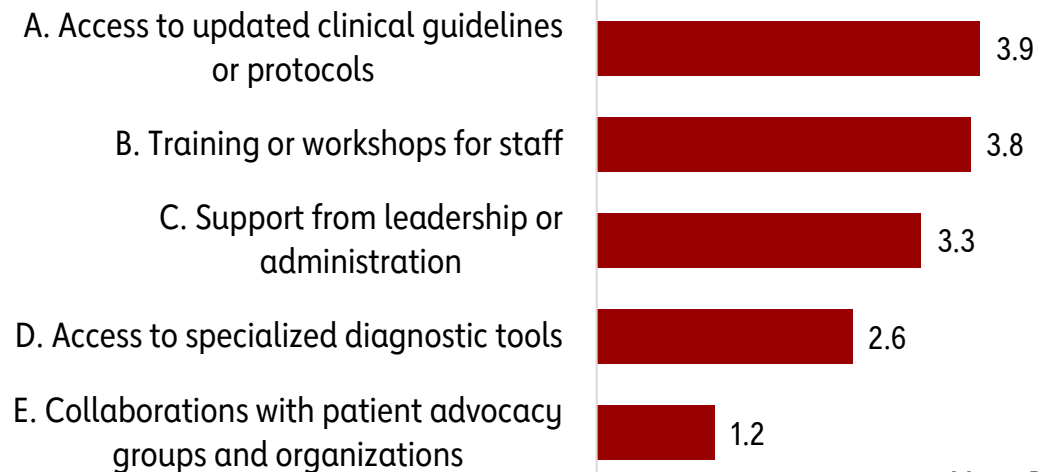
¹ Respondents were instructed to "Please rank from most effective to least effective." 5 Represents the most effective, 1 the least effective. The graph shows the mean ranking given by respondents.



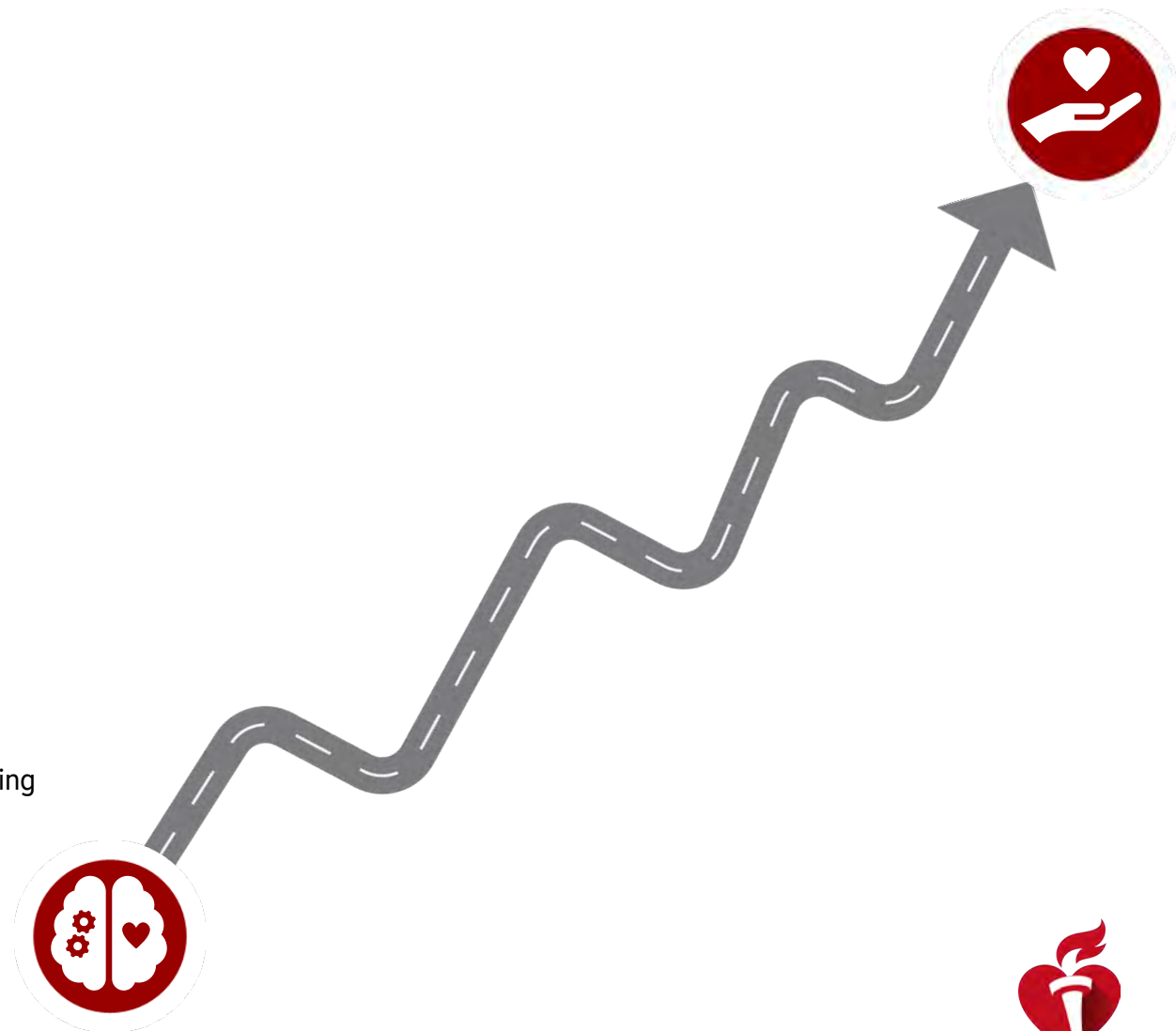
Respondents' Perspectives

POST

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

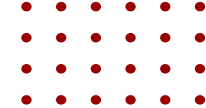


Mean Ranking



¹ 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

Accelerating Diagnosis. Advancing Multidisciplinary Care. Improving Outcomes.

Bridging Gaps in the AL-Amyloidosis Patient Pathway

In collaboration with expert panelists, researchers, and advocacy organizations, the American Heart Association (AHA) is advancing a nationwide initiative to identify and address critical gaps across the AL-Amyloidosis care continuum—ensuring earlier diagnosis, timely referrals to specialized care, and comprehensive patient support throughout the journey.


Spotlight: Patient Perspective & Expert Voices

At the heart of this initiative are the voices that matter most. Hear from leading clinicians driving progress—and a courageous patient whose story underscores the urgency and human impact of this work.



Quick Reference Guide

Front



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.

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


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

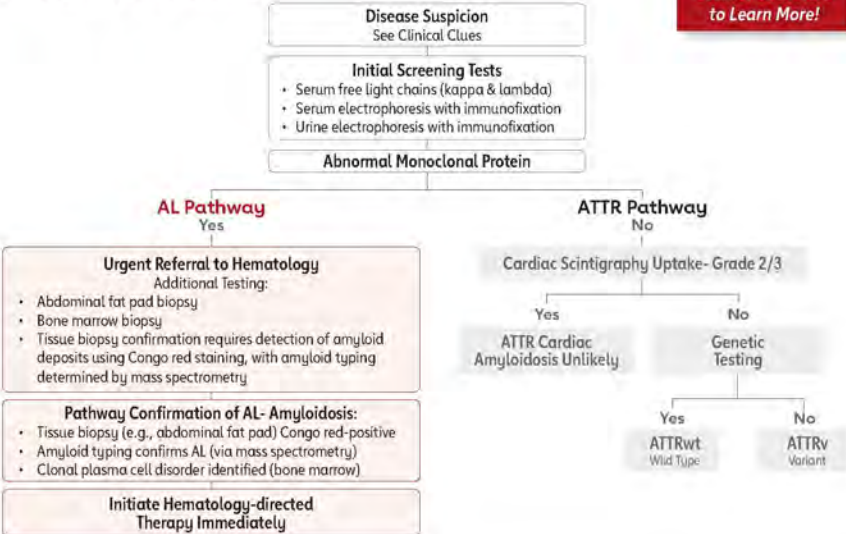
Back

AL-Amyloidosis Quick Reference Guide




Scan or Click Here to Learn More!

Diagnosing Amyloidosis




```
graph TD
    A[Disease Suspicion  
See Clinical Clues] --> B[Initial Screening Tests  
• Serum free light chains (kappa & lambda)  
• Serum electrophoresis with immunofixation  
• Urine electrophoresis with immunofixation]
    B --> C[Abnormal Monoclonal Protein]
    C --> D[AL Pathway  
Yes]
    C --> E[ATTR Pathway  
No]
    D --> F[Urgent Referral to Hematology  
Additional Testing:  
• Abdominal fat pad biopsy  
• Bone marrow biopsy  
• Tissue biopsy confirmation requires detection of amyloid deposits using Congo red staining, with amyloid typing determined by mass spectrometry]
    F --> G[Pathway Confirmation of AL-Amyloidosis:  
• Tissue biopsy (e.g., abdominal fat pad) Congo red-positive  
• Amyloid typing confirms AL (via mass spectrometry)  
• Clonal plasma cell disorder identified (bone marrow)]
    G --> H[Initiate Hematology-directed Therapy Immediately]
    E --> I[Cardiac Scintigraphy Uptake- Grade 2/3]
    I --> J[Yes]
    I --> K[No]
    J --> L[ATTR Cardiac Amyloidosis Unlikely]
    K --> M[Genetic Testing]
    M --> N[Yes]
    M --> O[No]
    N --> P[ATTRwt Wild Type]
    O --> Q[ATTRv Variant]
```




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



MACKENZIE'S MISSION
mm713.org




Amyloidosis Research Consortium
arci.org



AMYLOIDOSIS SUPPORT GROUPS
We are not alone.
www.amyloidosisupport.org


Clinician Pocket Card


Front


**American Heart Association**


AL-Amyloidosis
Clinician Pocket Guide


Clinical Clues


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

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

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Dyspnea, hypotension, edema, arrhythmias, increased L-Ventricular wall thickness

**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:



How this Toolkit Helps?!



From Awareness to Action — Tools That Make a Difference.



CALL TO ACTION



www.heart.org/AL-Amyloidosis

The screenshot shows the top navigation bar of the American Heart Association website. It includes a search bar with the text "Type to search...", a "Donate Once" button, and a "Donate Monthly" button. Below the navigation bar, there is a breadcrumb trail: [Home](#) / [Professional Resources](#) / [Quality Improvement](#) / [AL-Amyloidosis](#). The main content area features a large image of a doctor and a patient. Overlaid on the left side of this image is a white box with the text "AL-Amyloidosis Educational Toolkit". Below the image, there is a section titled "Accelerating Diagnosis. Advancing Multidisciplinary Care. Improving Outcomes." followed by the subtitle "Bridging Gaps in the AL-Amyloidosis Patient Pathway". The text continues: "In collaboration with expert panelists, researchers, and advocacy organizations, the American Heart Association (AHA) is advancing a nationwide initiative to identify and address critical gaps across the AL-Amyloidosis care continuum—ensuring earlier diagnosis, timely referrals to specialized care, and comprehensive patient support throughout the journey." Below this, there is a section titled "Spotlight: Patient Perspective & Expert Voices" with the text: "At the heart of this initiative are the voices that matter most. Hear from leading clinicians driving progress—and a courageous patient whose story underscores the urgency and human impact of this work."

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AL-Amyloidosis Educational Toolkit

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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

