



— NATIONAL —  
MINORITY QUALITY  
— FORUM —

# Speak Up for ATTR-Cardiac Amyloidosis

A Social Media Toolkit for Awareness & Action



Naomi\_Violet

Actor portrayals.



Calls to Action

## Signs of ATTR-CM



362



12



This toolkit is designed to help patients, caregivers, and advocates raise awareness about ATTR-cardiac amyloidosis (ATTR-CM). By using social media, you can educate communities, encourage earlier diagnosis, and support those affected by this rare but serious condition.

## Below are a few key messages to include in your social media posts

### What is ATTR-CM?

ATTR-CM is a disease that gets worse over time. It happens when transthyretin (TTR) proteins, important proteins that carry key hormones and vitamins in your body, become unstable, misfold, and start to build up in the body, especially in the heart.

### Who Is at Risk?

ATTR-CM can be hereditary (hATTR-CM) or wild-type ATTR (wtATTR-CM) and affects both men and women. Some populations, especially Black individuals with the V122I gene change, may have a higher chance of getting the condition.

### Symptoms to Watch for



#### Heart-related symptoms

Irregular heartbeat, heart failure, shortness of breath, swelling in legs



#### Nerve-related symptoms

Numbness, tingling, pain, carpal tunnel syndrome, difficulty walking

### Why Early Diagnosis Matters

ATTR-CM is often mistaken for other conditions like heart failure or nerve problems. Catching it early with genetic testing, scans, or a biopsy can lead to better treatment results.

### Available Treatment Options

While there is no cure, treatments can slow progression. Ask your healthcare provider about medications that can help maintain heart health for as long as possible, such as those that can stabilize the TTR proteins so that they are less likely to misfold.

### Advocate for Awareness

Many people remain undiagnosed due to lack of awareness. Sharing information can help extend lives.

## Use these hashtags to increase visibility and engagement

#ATTRCMAwareness

#RareDisease

#GeneticTesting

#KnowATTRCM

#HeartHealth

#CardiacAmyloidosis



## Sample Social Media Posts

---

Copy and paste these posts directly into your social media or edit these messages to your preference.

### What is ATTR?

#### Post 1

🚩 Did you know?

ATTR-cardiac amyloidosis (ATTR-CM) is a progressive condition that affects the heart. Many cases go undiagnosed, leading to serious complications. Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).

**Learn the signs and get tested! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#ATTRCMAwareness #KnowATTRCM #HeartHealth

### Who is at Risk?

#### Post 2

Certain populations, including Black individuals with the V122I gene change, are at a higher risk for hereditary ATTR-CM. If heart failure runs in your family,

**Talk to your doctor about genetic testing. Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#KnowATTRCM #GeneticTesting #RareDisease ❤️

#### Post 3

Did you know?

Black individuals with the V122I gene change have a higher risk of hereditary ATTR-CM. Wild-type ATTR-CM (wtATTR-CM) can also affect individuals from any background and is caused by aging.

**If heart failure runs in your family, ask about genetic testing! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#GeneticTesting #ATTRCMAwareness #CardiacAmyloidosis



## Symptoms to Watch For

### Post 4

⚠️ Do you or a loved one have unexplained heart failure, low back pain, or carpal tunnel syndrome? It could be ATTR-CM. Many people are misdiagnosed—early detection is key!

**Learn more: Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#ATTRCMAwareness #HeartHealth

### Post 5

Unexplained shortness of breath? Swelling in your legs? These could be symptoms of ATTR-CM.

**Talk to your doctor today! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#KnowATTRCM #EarlyDetection 🩺

### Post 6

Many people with ATTR-CM are misdiagnosed and have a history of conditions like carpal tunnel syndrome, biceps tendon ruptures, and heart failure.

**Let's change that—learn the signs and get tested! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#KnowATTRCM #EarlyDetection ⚠️

## Early Diagnosis Matters

### Post 7

ATTR-CM is often mistaken for common heart and nerve conditions, delaying critical treatment. The right tests can make all the difference.

**Don't wait—talk to your doctor today! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**

#KnowATTRCM #EarlyDetection #RareDisease 📄



## Available Treatments

### Post 8

Living with ATTR-CM?

There are potential treatments that can slow progression of the condition and improve health-related quality of life.

**Stay informed and speak to your healthcare provider. Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**  
#TreatmentOptions #ATTRCMAwareness #HeartHealth 


### Post 9

here's hope for people living with ATTR-CM! While there's no cure, potential treatments can slow progression of the condition and improve health-related quality of life.

**Stay informed and speak to your healthcare provider. Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**  
#TreatmentOptions #ATTRCMAwareness 

## Join the Movement

### Post 10

 Raise your voice for ATTR-CM awareness! Many people remain undiagnosed.

**Share this post to help spread the word and save lives. Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**  
#KnowATTRCM #PatientAdvocacy #RareDisease

### Post 11

Together, we can raise awareness about ATTR-CM.

**Like, comment, and share this post to spread the word! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).**  
#KnowATTRCM #HeartHealth 



## Share Your Story

Post 12

Your voice matters!

If you or a loved one has been affected by ATTR-CM, sharing your story can help others get diagnosed sooner.

Use #ATTRCMAwareness and make an impact today! Visit [www.askaboutATTR.org](http://www.askaboutATTR.org).

Link to graphics:



## Engagement Strategies

Engagement is key to spreading awareness about ATTR-CM. Building an active and informed community can amplify important messages and encourage early diagnosis. Using a mix of storytelling, visual content, and interactive discussions can make advocacy efforts more impactful.



### Tag National Minority Quality Forum (NMQF)

Mention groups like NMQF or other relevant organizations to increase reach.



### Use Infographics

Visual content gets more engagement. Create simple graphics highlighting symptoms, risks, and treatment options.



### Share Personal Stories

Encourage patients and caregivers to share their experiences with ATTR-CM.



### Host Q&A Sessions

Consider live Q&A sessions with healthcare professionals or patient advocates.



For more information on ATTR-CM, visit [www.askaboutATTR.org](http://www.askaboutATTR.org).

