



# Minutes of the Meeting: "Unveiling Amyloidosis: Bridging Knowledge & Patient Care" Webinar

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**Date:** October 26, 2024

**Time:** 7:30 PM - 9:30 PM IST

**Topic:** Issues, Challenges, and Emerging Solutions to Combat Amyloidosis

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**Organized by:** Amyloidosis Support Group of India (ASGI) SDG initiative by RDSSDF in collaboration with DGHS, MoHFW, Gol, and IMAGE-India

## **IMAGE (Indian Myeloma Academic Group)**

IMAGE focuses on promoting research, awareness, and support for myeloma and plasma cell disorders in India and neighbouring regions. They organize educational events, establish treatment guidelines, and provide resources to improve patient care for plasma cell disorders.

## **DGHS (Directorate General of Health Services)**

Under the Ministry of Health and Family Welfare, DGHS plays a pivotal role in health policy, national health programs, and medical services, including initiatives for rare diseases like amyloidosis.

## **MoHFW (Ministry of Health and Family Welfare)**

The MoHFW oversees India's healthcare regulations, policies, and public health efforts, actively working to improve care accessibility and resources for rare diseases, including amyloidosis.

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**Chairperson:** Dr Atul Jonwal, Department of Health Services, MoHFW

## **Dr Atul Jonwal**

Dr Atul Jonwal, from the Department of Health Services (MoHFW), is a key figure in advancing public health initiatives and policies in India.

### **Organizing Committee:**

- **Dr Satish Chandra** - Founder, ASGI
- **Mr. Atul Pandya**
- **CS. Shriya Bhargav**
- **Soumya Banerjee**
- **Soumya Dasgupta & Team**
- **Ms. Navodita Seth** - Design Partner (VIZVE Design)

### **Participants and Special Partners:**

1. **Col. (Dr) Uday Yanamandra** - Secretary, IMAGE
  2. **Dr Gurleen Oberoi** - Senior Consultant, Hematopathology
  3. **Dr B.S. Vivek**
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### **Webinar Objectives:**

The webinar aimed to:

1. Raise awareness of amyloidosis and its impact on patients.
  2. Address diagnostic challenges and promote early diagnosis.
  3. Enhance knowledge on the latest treatment options and research.
  4. Support access to cost-effective treatments.
  5. Highlight patient-centered care approaches.
  6. Advance policies and infrastructure for amyloidosis care.
  7. Facilitate international knowledge exchange.
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### **Key Discussions:**

- **Opening Remarks**

**Speaker:** Dr Satish Chandra

**Time:** (7:30 PM - 7:40 PM)

Dr Chandra welcomed all participants and expressed gratitude for the collaboration between ASGI and IMAGE, DGHS, and MoHFW.

He highlighted the urgent need to improve awareness about amyloidosis among healthcare professionals and the general public.

He noted the challenges faced by patients due to the disease's late diagnosis and limited access to specialized care.

Emphasized the objective of advocating for amyloidosis to be recognized as a rare disease in India, which would bring regulatory support and facilitate patient access to necessary treatments and financial assistance.

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- **Initial Discussion:**

**Speaker:** Col. (Dr) Uday Yanamandra

Time: (7:40 PM - 7:55 PM)

Col. (Dr) Uday Yanamandra initiated a dialogue concerning diagnostic challenges, particularly focusing on kidney involvement in amyloidosis and the importance of rectal biopsies. He mentioned that while gut biopsies are effective for diagnosis, kidney function can remain normal despite the presence of amyloidosis

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- **Special Address**

**Speaker:** Dr Atul Jonwal

Time: (7:55 PM – 8.05 PM)

Dr Jonwal discussed on the elusive nature of amyloidosis, a condition characterized by non-specific early symptoms like fatigue and unexplained weight loss. These early signs often go unnoticed, leading to a delay in diagnosis until organ damage is already advanced. Dr Jonwal emphasized that common organ manifestations—such as nephropathy, cardiomyopathy, and neuropathy—can serve as indicators for healthcare practitioners to suspect amyloidosis.

Dr Jonwal highlighted the importance of vigilance in early identification, urging practitioners to consider amyloidosis in cases where multiple systems are affected and unexplained weight loss, fatigue, or abnormal heart or kidney function is present. He encouraged physicians to familiarize themselves with amyloidosis markers to ensure timely diagnosis and reduce the progression to end-stage organ damage, which is commonly observed in amyloidosis patients.

**Challenges in Diagnostics**

In government healthcare setups, where resources are limited, Dr Jonwal noted that specialized tests like electrophoresis and specific biopsies are often inaccessible to low-income populations. He stressed the need for affordable diagnostic tools in rural and under-resourced healthcare settings. Dr Jonwal highlighted that many patients are lost to follow-up when expensive tests are ordered, underscoring the pressing need to make essential diagnostics more accessible.

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- **Technical Session**

**Speaker:** Col. (Dr) Uday Yanamandra - Secretary, IMAGE (Moderator), Dr. Gurleen Oberoi, Dr B.S. Vivek.

Time: (8.05 PM – 9.20 PM)

- **Advanced Diagnostic Techniques and Challenges in Diagnosis:**

**Speaker:** Dr Gurleen Oberoi,

Dr Oberoi offered an in-depth overview of the diagnostic challenges specific to amyloidosis. She explained that because amyloidosis often manifests with patchy tissue involvement, traditional biopsies may fail to capture the condition if only a single tissue site is sampled. She underscored the need for high clinical suspicion, along with multiple biopsies, to confirm amyloidosis.

**Genetic Mutations and Diagnostic Protocols:**

Dr Oberoi also discussed hereditary amyloidosis, noting genetic mutations commonly associated with the disease, such as transthyretin mutations. She highlighted that these genetic factors often present with symptoms affecting the heart and nervous system, making it challenging to diagnose without specific genetic testing.

**Use of Congo Red Staining and Immunofluorescence:**

Dr Oberoi described the role of Congo red staining and immunofluorescence in diagnosing amyloidosis. The apple-green birefringence under polarized light seen in Congo red staining is a key diagnostic indicator, though its interpretation requires specialized expertise. Given the limited availability of resources, Dr. Oberoi called for the standardization of diagnostic protocols and the adoption of efficient, cost-effective methods for amyloidosis detection across healthcare settings in India.

**Mass Spectrometry and Proteomics:**

Dr Oberoi highlighted the promising role of mass spectrometry and proteomics for amyloidosis diagnostics. Mass spectrometry, which allows for precise identification of amyloid proteins, represents an advanced diagnostic tool, though it is still in early stages in India. Dr Oberoi cited ongoing collaborative efforts to adapt mass spectrometry methods for cost-effective usage in India, noting Proteomics' work with Lal Path Labs as an example of how diagnostic innovations are being developed domestically.

- **Management of Amyloidosis-Related Complications:**

**Speaker:** Dr B.S. Vivek

Dr Vivek discussed the clinical management of amyloidosis, focusing on cardiac involvement, which is common in amyloidosis patients. He explained the "cherry on top" sign, a characteristic pattern seen in cardiac imaging of amyloidosis patients, and its relevance as a diagnostic marker. However, Dr Vivek cautioned that while the sign is sensitive, it is not entirely specific to amyloidosis and must be used alongside other diagnostic tests.

**Blood Pressure and Heart Management:**

Dr Vivek noted that amyloidosis often leads to restrictive cardiomyopathy, which decreases the heart's ability to fill with blood properly and results in lower blood pressure. Patients often experience episodes of low blood pressure, and Dr Vivek

recommended managing these symptoms with diuretics and calcium channel blockers, which can help control fluid overload and support heart function.

**Patient-Centred Approaches:**

He emphasized a patient-centred approach to treatment, which involves tailoring treatment plans to the individual needs of each patient. Given amyloidosis' impact on multiple organ systems, a personalized care strategy is critical for maintaining quality of life and addressing specific symptoms.

- **Future of Diagnostic Technology: Mass Spectrometry and SAP Scanning:**  
**Speakers:** Dr Gurleen Oberoi and Col. (Dr) Uday Yanamandra

Dr Oberoi and Col. Yanamandra discussed the future role of advanced diagnostic techniques in amyloidosis care, focusing on mass spectrometry and SAP (serum amyloid P) scanning. Mass spectrometry's ability to identify amyloid protein types with high precision was highlighted as a potential game-changer for diagnosis and research. Dr Oberoi mentioned an innovative, cost-effective mass spectrometer method being developed by Dr Nikita Mahav, which could make diagnostics more accessible to Indian hospitals and clinics.

**SAP Scanning for Prognostic and Diagnostic Use:**

Dr Oberoi discussed the use of SAP scanning; a technique widely used in the UK to track amyloidosis progression and assess treatment efficacy. She shared that while SAP scanning is currently rare in India, its adoption could provide valuable prognostic insights, helping clinicians monitor disease progression and evaluate treatment response.

**Collaborations with Industry and Research Institutions:**

Col. Yanamandra noted that companies such as Proteomics and Sebia are actively working to bring mass spectrometry and other diagnostic tools to India. Collaborative efforts between these companies, research institutions, and clinical settings could significantly expand diagnostic capabilities in the near future.

- **Patient Queries and Expert Answers:**

**Soumya Banerjee** raised a question concerning **urine output** in a patient, seeking clarity on how kidney functions correlate with amyloidosis progression. **Dr Uday** responded by explaining that while amyloidosis primarily affects kidneys, patients may not always show dramatic symptoms until later stages. He stressed the importance of regular monitoring.

**Miss Shriya** inquired about her father's renal amyloidosis, specifically regarding fluctuations in free light chain (FLC) numbers after a kidney transplant. Dr Uday addressed her concerns, explaining that while the FLC ratio is crucial, fluctuations

can occur and are generally not alarming if monitored closely. He emphasized the need for ongoing observation and consultations with healthcare providers.

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- **Patient Experiences:**

Time: (9.20 PM – 9.25PM)

**Sonali Jain**, a patient diagnosed with **AL amyloidosis**, shared her journey. She described the numerous challenges she faced in obtaining a correct diagnosis, which involved multiple misdiagnoses and tests. Her emotional testimony emphasized the **mental, physical, and financial burden** of amyloidosis. Her experiences highlighted the need for greater awareness and support systems for amyloidosis patients.

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- **Concluding Remarks**

**Speaker:** Dr Satish Chandra

Time: (9.25 PM – 9.35 PM)

**Advocacy and Policy Development for Amyloidosis** Dr Chandra advocated for recognizing amyloidosis as a rare disease in India's healthcare policy. Inclusion in the rare disease registry would make patients eligible for government support, including financial assistance and access to specialized treatments. Dr Chandra noted that amyloidosis patients often face severe financial burdens due to high treatment costs, making policy support crucial for long-term management and access to care.

**Building a Collaborative Framework**

Dr Chandra proposed a partnership with IMAGE and other research institutions to strengthen amyloidosis research and patient care infrastructure. By sharing ASGI's database of amyloidosis cases and volunteer resources, he suggested that collaborative studies could be conducted to improve diagnostic approaches and treatment options.

**Proposal for Centres of Excellence**

Dr Chandra outlined his vision for establishing dedicated amyloidosis centres in major cities across India. These centres, staffed by trained specialists and equipped with diagnostic tools, would provide essential support to amyloidosis patients nationwide. Dr Chandra expressed optimism that collaboration with the Ministry of Health and Family Welfare (MoHFW) and the Directorate General of Health Services (DGHS) could lead to the development of such centres.

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- **Vote of Thanks:**

**Speaker:** Ms. Navodita Seth

Time: (9.35 PM – 9.40 PM)

Ms. Navodita Seth concluded the webinar by thanking all participants, particularly Dr. Uday for his insightful contributions and the IMAGE team for their assistance. She acknowledged Dr Atul Jonwal and Dr Gurleen Oberoi for addressing patient questions effectively, enhancing their understanding of the disease.

Navodita also recognized the hard work of Satish Chandra and the entire ASGI team in making the event successful, noting that all recordings and data would be shared in the ASGI group for further reference and connectivity among participants.

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- **Closing Remarks:**

The meeting concluded with a photography session to document the gathering. Participants were encouraged to engage with the ASGI group's resources and updates on social media platforms.

