

# Unveiling Amyloidosis :

## Bihar Chapter



# Acknowledgments

We extend our heartfelt gratitude to each individual and organization that made the "Unveiling Amyloidosis: Bihar Chapter" webinar, held on 3<sup>rd</sup> December a success. This gathering was successful because of the dedication, collaboration, and expertise of so many people committed to improving the lives of those affected by amyloidosis.

We would like to express our sincere gratitude to Hon'ble Prime Minister Shri Narendra Modi for his unwavering support and dedication to our cause. His encouragement inspires us to work harder and make a meaningful difference in the Amyloidosis community.

We would like to express special thanks to IMAGE-India. We are immensely grateful for the role Dr. Pankaj Malhotra (President, IMAGE) and Col. Dr. Y. Uday (Secretary, IMAGE), for have played in expanding awareness and driving research in this vital field. & for their invaluable partnership and support.

We are deeply grateful for the unwavering support and dedication of Prof. (Dr.) Satish Chandra, founder and facilitator of this event, whose vision and leadership brought together the best minds to address the challenges of amyloidosis. Prof. Chandra's commitment to this cause has set a high standard for collaborative and patient-centred healthcare.

Our heartfelt thanks also go to the entire team at RDSSDF, ASGI & VIZVE Design, for their support & tireless work behind the scenes to ensure the smooth execution of the event.

Thank you once again to every participant, organization, and supporter. Your contributions have made a significant difference in bridging knowledge gaps and enhancing patient care in the field of amyloidosis. Together, we are creating a brighter, healthier future for all.

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# Webinar Details:

**Date:** December 3, 2024

**Time:** 7:00 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) a initiative by RDSSDF under SDG 3.

**Organizers:**

- Prof. (Dr.) Satish Chandra Founder & Facilitator of ASGI, Mr. Atul Pandiya, Miss Shriya and the ASGI team.
  - Navodita Seth design partner (VIZVE Design)
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**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.

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**Chairperson:** Dr. Avinash Kumar - Senior Haematologist & Chairman, Bihar Chapter, ASGI

**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)

### **Special Partners:**

Amyloidosis Support Group of India (ASGI) organized the Webinar in collaboration with IMAGE-India

V. **Dr. Pankaj Malhotra** - President, IMAGE

VI. **Col. (Dr.) Uday Yanamandra** - Secretary, IMAGE



### **Institutional Well-wishers:**

1. Fortis Institute of Blood Disorders, Gurgaon
2. Paramhans Institute of Neurology Patna
3. Patna Hematology Hemato-Oncology Patna ,Bihar

**Moderator: Dr. Gurleen Oberoi**- Senior Consultant Hematology Medanta, Gurgaon.

### **Speakers :**

- I. Dr. B.S. Vivek – Senior Cardiologist at Sir Ganga Ram Hospital
- II. Dr. Nikita Mehra – Hematologist & Oncologist, Chennai
- III. Dr. Sanjay Kumar – HoD of Neurology, PMCH, Patna, Bihar
- IV. Dr. Sandeep Seth – Senior Cardiologist, AIIMS, New Delhi
- V. Dr. Nikhil Kumar- Fortis Hospital

## 1. Abstract:

The **Amyloidosis** webinar, titled "**Unveiling Amyloidosis: Bihar Chapter,**" was held on December 3<sup>rd</sup>, 2024, as a collaborative initiative led by the Amyloidosis Support Group of India (ASGI) and supported by Dr. Avinash Kumar - Senior Haematologist & Chairman, Bihar Chapter, ASGI & IMAGE-India. Hosted under the framework of the RDSSDF's Sustainable Development Goal (SDG) 3, the event aimed to address the critical need for awareness, improved diagnostics, and accessible treatment options for amyloidosis—a rare and complex disease that often goes undiagnosed or misdiagnosed until late stages.

The webinar brought together healthcare professionals, policymakers, researchers, patients, and advocates from across India and abroad to exchange insights, discuss challenges, and explore solutions to improve amyloidosis care. It provided a comprehensive platform for understanding the disease, its impact on patients, and the structural and clinical gaps within India's healthcare system. The discussions underscored the importance of adopting patient-centred approaches, expanding diagnostic capabilities, and fostering research collaborations to tackle the rising incidence of amyloidosis.

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## 2. Introduction and Background

Amyloidosis is a complex, life-threatening condition caused by the abnormal deposition of amyloid fibrils—insoluble protein aggregates—in tissues and organs. These deposits disrupt normal organ function, particularly in the heart, kidneys, liver, and nervous system, leading to severe health complications and, often, irreversible damage. Due to its rarity and the non-specific nature of its symptoms, amyloidosis is frequently underdiagnosed or misdiagnosed. This diagnostic challenge delays treatment and significantly contributes to high morbidity and mortality rates.

In India, amyloidosis remains an underreported and poorly understood condition. The limited awareness among healthcare providers and the general population, coupled with the lack of adequate diagnostic infrastructure, exacerbates the challenges in timely diagnosis and treatment. Additionally, the diverse healthcare landscape in India, with significant disparities in access to specialized care, makes it even more difficult for patients in rural and underserved areas to receive appropriate medical attention. The condition often remains undetected until it reaches advanced stages, leading to high treatment costs and severe outcomes for patients and their families. Current therapies in India are primarily focused on symptom management, with limited availability of advanced diagnostic tools and targeted treatments. These gaps underline the critical need for increased awareness, enhanced diagnostic capabilities, and research into cost-effective therapeutic strategies to improve outcomes for Indian patients with amyloidosis.

Unveiling Amyloidosis: Bihar Chapter is ASGI's 1<sup>st</sup> initiative under Bihar Chapter. As part of the Amyloidosis Support Group of India's (ASGI) commitment to advancing amyloidosis care under Sustainable Development Goal (SDG) 3: Good Health and Well-being, the "Unveiling Amyloidosis: Bihar Chapter" webinar marked a significant step in addressing regional challenges. ASGI has set an ambitious target of establishing 36 regional chapters (28 states and 8 union territories) across India by the end of 2025. These chapters aim to address local challenges faced by patients, families, and medical institutions, ensuring early diagnosis and initiating timely treatment.

The webinar, organized by ASGI in collaboration with IMAGE-India (Indian Myeloma Academic Group), brought together an interdisciplinary panel of stakeholders, including

healthcare providers, policymakers, researchers, patient advocates, and academic experts. With design and execution led by Vizve Design, the event facilitated insightful discussions on diagnosis, treatment, and patient support for amyloidosis, emphasizing the need for comprehensive, accessible, and affordable healthcare solutions.

The event also underscored the importance of regional initiatives in raising awareness and fostering ground-level support for those affected by the disease & announced ASGI's initiative for Amyloidosis of Bihar Centre. Discussions highlighted the potential for technological innovations such as a **national patient database** to streamline diagnosis and follow-up care. Policy recommendations focused on building infrastructure and providing financial and logistical support to enhance amyloidosis care.

The "**Unveiling Amyloidosis: Bihar Chapter**" demonstrated ASGI's dedication to creating a sustainable framework for addressing the unmet needs of amyloidosis patients in India. The initiative aligns with SDG 3, promoting health equity and patient-centered solutions to improve outcomes and quality of life for those impacted by this challenging condition.

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### **3. Objectives of the Webinar**

The World Amyloidosis Day webinar was designed to achieve several key objectives:

**3.1.Raise Awareness:** The webinar sought to raise public awareness of amyloidosis, highlighting the disease's symptoms, impact, and the importance of early diagnosis. By educating both healthcare professionals and the general public, the event aimed to foster a more informed and supportive environment for amyloidosis patients.

**3.2.Address Diagnostic Challenges:** Amyloidosis is often diagnosed late due to its symptoms' similarity to more common diseases, which can lead to significant organ damage by the time it is recognized. The webinar addressed these diagnostic challenges, presenting emerging tools and protocols that could facilitate earlier and more accurate diagnosis, especially in resource-limited settings.

**3.3.Enhance Knowledge of Treatment and Research:** Given the limited treatment options and high costs associated with amyloidosis care, the webinar provided a forum to explore



the latest research and developments in diagnostic and therapeutic options. Participants gained insights into emerging treatments and current research directions, which aim to make care more accessible and effective.

**3.4.Promote Collaborative Research and Policy Advocacy:** To drive sustainable solutions for amyloidosis, the event emphasized the importance of collaborative research and policy support. Partnerships among healthcare institutions, researchers, and policymakers are essential to developing affordable treatments, enhancing diagnostics, and establishing care frameworks for rare diseases like amyloidosis.

**3.5.Support Patient-Centred Approaches:** The webinar highlighted the importance of personalized treatment plans and holistic care approaches tailored to the unique needs of amyloidosis patients. This patient-centred focus aims to improve quality of life, address the physical and emotional challenges associated with the disease, and ensure that patients receive ongoing, comprehensive care.

**3.6.Influence Policy and Infrastructure Development:** The event advocated for including amyloidosis within India's rare disease policy framework, which would provide patients with better access to financial support, specialized treatment options, and public healthcare resources. Policy advancements are necessary to build a stronger infrastructure for rare disease management in India.

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#### **4. Primary Outcomes and Insights:**

The discussions generated critical insights and recommendations:

##### **4.1.Awareness and Education**

- The event emphasized the rarity and challenges associated with diagnosing and treating amyloidosis.
- Key presentations by medical experts, including Dr. Gurleen Oberoi and Dr. Nikita Mehra, shed light on advancements in diagnostic tools like mass spectrometry and improved treatment strategies.

##### **4.2. Collaborative Knowledge Exchange**

- The webinar facilitated discussions among national and international experts, such as Dr. Sanjay Kumar and Dr. Vivek, who shared their experiences and research findings.

- Topics ranged from genetic mutations and diagnostic protocols to innovations in treatments like CAR-T cell therapy and autologous stem cell transplantation.

#### **4.3. Patient-Centric Support**

- The Q&A session provided patients and caregivers with direct access to experts to discuss their concerns.
- Questions about treatment costs, FLC monitoring, biopsy protocols, and post-treatment care were addressed in detail.
- The need for localized and affordable care systems was highlighted, particularly for underserved regions in India.

#### **4.4. Policy and Infrastructure Initiatives**

- The ASGI outlined its vision for a national patient portal and database, focusing on seamless data collection and patient tracking.
- Suggestions for telemedicine, digital health initiatives, and policy campaigns to support rare disease management were discussed.

#### **4.5. Future Directions**

- Research Collaboration: Expansion of the cohort for studies on diagnostic techniques like mass spectrometry to enhance accuracy and reduce costs.
- Localized Chapters: Plans for state-level chapters, to provide localized support and facilitate grassroots awareness campaigns.
- Awareness Events: Increased frequency of webinars and seminars to educate healthcare professionals and patients.

### **5. Agenda and Schedule**

<b>Time</b>	<b>Session</b>	<b>Speaker</b>
7.00 PM - 7.05 PM	Opening Remarks	Dr. Satish Chandra
7.05PM - 7.10 PM	Initial Discussion on Diagnostic Challenges	Dr. Avinash Kumar Senior Hematologist & Chairman, Bihar Chapter, ASGI

<b>Time</b>	<b>Session</b>	<b>Speaker</b>
7.10 PM- 7.25 PM	Introduction, ASGI	Navodita Seth & Team Vizve Design, Design Partner RDSSDF
7.25PM - 8.45 PM	Preliminary Overview & Technical Session	Dr. Gurleen Oberoi Senior Consultant Hematology Medanta, Gurgaon.
8:45 PM - 9:15 PM	Interactive Q&A Panel	Moderated by Col. Uday Yanamandra , Shriya Bhargav Singh, Atul Pandya
9:15 PM - 9:30 PM	Concluding Remarks and Vote of Thanks	Dr. Satish Chandra, & Dr. Gurleen Oberoi

## 6. Participants and Attendees

### List 1

Prof. (Dr.) Satish Chandra

Mr. CP Verma

Soumya Banerjee

Dr. B.S. Vivek

Dr. Sandeep Seth

Abhash Sinha

Akhilesh Kumar P.H

Anannya Indra Kashyap

Arun Gupta

Astha Health Care Wellness

Avinash Singh

Baghath Singh Ananthanarayanan

Chandana Wickramaratne Kurukula  
Arachchi

Dilip Kumar Mazumdar

### List 2

Dr. Avinash Kumar

Mr. Atul Pandya

Navodita Seth

Dr. Nikita Mehra

Dr. Nikhil Kumar

Ahsanul Mazid

Alok Kumar

Aquib Hussain

Arunima

Atul Jain

Ayan Santra

Bharat Jindal

Chanderprakash Verma

Gian Bansal

### List 3

CS Shriya Bhargav

Somanath Padhi

Dr. Gurleen Oberoi

Dr. Sanjay Kumar

Ramabrata Chatterjee

Ajay Jha

Amit Rai

Arti Bansal

Ashish Bhargava

Atul Yadav

B.P. Singh

Bhawana Agrawal

Debashis Bhattacharya

Hari Haran

<b>List 1</b>	<b>List 2</b>	<b>List 3</b>
Hima	Humayra Nazneen	Jainendra Upadhyay
Jyoti Sawhney	Kavitha Jayaprasad	Koshalya Kumari
Mahadev Harani	Main Block First Floor, SRMC	Manashi Ghosh
Menakadevi Suresh	Midhila Baby	Moti Lal Sharma
Mridul Indane	Mukesh Sharma	Nabajit Dewgharia
Naresh Tayade	Nikhil Dubey	Nikhil Kumar
Noob Players	Nutan Joshi	Paramhans Institute of Neurology
Parveen M	Premyouthfoundation PYF	Rajiv Prasad
Ramendra Verma	Ranjan Singh	Rashmi Bhargava
Rishu Vidhatri	Sachin Nirola	Sant Prakash Kataria
Sayli Dhande	Shalini Singh	Tejaswini Gudibande
Twisha Chandra	Vinod Kumar	

The event saw wide participation from healthcare professionals, policymakers, researchers, and amyloidosis patients.

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## **7. Webinar summery**

### **7.1.Opening Remarks: Dr. Satish Chandra**

Dr. Chandra opened the webinar by welcoming all participants, including patients, healthcare professionals, and researchers. He provided a brief background on amyloidosis, a rare disease with significant diagnostic and treatment challenges, and explained ASGI's role as a pioneering initiative to tackle these obstacles.

He emphasized the need for multidisciplinary collaboration to address the complexity of amyloidosis and introduced the evening's agenda, highlighting discussions on diagnosis, treatment advancements, and patient care strategies.

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## 7.2. Session Summaries

### 7.2.1. Inaugural Address

**Speaker:** Dr. Avinash Singh - Senior Hematologist & Chairman, Bihar Chapter, ASGI

Dr. Avinash Singh's inaugural address was a concise yet impactful introduction to the webinar, focusing on the need for concerted efforts to address the challenges posed by amyloidosis. His remarks were aligned with the webinar's objectives, emphasizing clinical aspects, patient care, and the importance of collaboration.

Dr. Singh began by addressing the participants and expressing his gratitude for being part of the session. He acknowledged the significance of the event in creating awareness and advancing care for a disease as rare and complex as amyloidosis.

**Supporting the ASGI Initiative:** He praised the **Amyloidosis Support Group of India (ASGI)** for taking the initiative to bring together experts, patients, and caregivers on a single platform to share knowledge and resources.

**Importance of Multidisciplinary Involvement:** Dr. Singh highlighted the critical role of a **multidisciplinary approach** in addressing amyloidosis. He stressed that the disease involves multiple organ systems, requiring coordinated efforts among specialists, including hematologists, neurologists, cardiologists, and nephrologists.

**Diagnostic Complexity:** Dr. Singh emphasized that the diagnosis of amyloidosis often involves piecing together symptoms from various disciplines. Misdiagnosis or delayed diagnosis is common due to the rarity of the disease and its varied presentations.

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### 7.2.2. Overview of ASGI and its Vision

**Speaker:** Navodita Seth, ASGI Design Partner

**Overview of ASGI's Mission:** Navodita Seth explained ASGI's vision, which aligns with **Sustainable Development Goal (SDG) 3** – ensuring healthy lives and promoting well-

being for all. ASGI's objectives include improving the landscape of amyloidosis care, increasing awareness, fostering medical collaborations, and addressing challenges related to diagnosis, treatment, financial access, and emotional support for patients.

**Prevalence and Challenges:** She shared alarming statistics to emphasize the gravity of the situation:

- **Global Impact:** By 2018, there were 74,000 global cases of amyloidosis, which translates to approximately 10 cases per million per year.
- **Indian Context:** In India, **40 cases of cardiac amyloidosis** were diagnosed between 1987 and 2017, and younger patients are more frequently affected.

**Patient Challenges:** She elaborated on the key challenges faced by amyloidosis patients in India:

- **Diagnosis:** Due to the rarity of the disease, many cases go undiagnosed for years.
- **Treatment Access:** High treatment costs and limited access to advanced therapies contribute to the challenges.
- **Social and Emotional Support:** Many patients face stigmatization, which compounds the physical challenges of the disease.

**ASGI's Projects:** She outlined ASGI's ongoing and upcoming projects, including:

- Development of a **national patient portal** for amyloidosis, aiming to create a centralized database of patients.
- **Collaboration with medical professionals** and pharmaceutical companies to improve patient access to treatment.
- **Public Awareness Campaigns** via webinars, social media, and other platforms to educate both the general public and healthcare professionals.

**Vision for the Future:** She closed by mentioning that ASGI aims to advocate for better healthcare policies and improve funding for rare diseases like amyloidosis.

### 7.2.3. Special Address

**Speaker:** Dr. Gurleen Oberoi - Senior Consultant Hematology, Medanta, Gurgaon

Dr. Gurleen Oberoi conducted a session focusing on the challenges in diagnosing and treating amyloidosis. Below is a summary of the key points discussed during the session

Dr. Gurleen discussed the importance of collaboration between ASGI & the Indian Myoma Academic Group (IMAGE)

These collaborations focus on:

- Improving disease prognosis through awareness.
- Addressing diagnostic challenges and increasing general knowledge about amyloidosis.
- Supporting research to address both emotional and physical challenges faced by patients.

Dr. Gurleen emphasized that policy-making efforts should aim at improving care for amyloidosis patients. She noted that, Collaboration and events are crucial for spreading knowledge about rare diseases such as amyloidosis.

Dr. Gurleen described the challenges involved in diagnosing amyloidosis, which include:

- The presentation of multiple symptoms or complications, making diagnosis difficult.
- The use of nonspecific protocols for the first diagnosis, which often leads to difficulties in identifying the disease.
- The need for painful procedures, such as biopsies, and the importance of using advanced techniques like polarized microscopy and cytogenetic analysis for diagnosis.

#### **7.2.4. Technical Session Highlights**

The technical session focused on diverse aspects of amyloidosis. It featured leading experts sharing clinical insights, diagnostic techniques, and therapeutic strategies.

**Moderator :** Dr. Gurleen Oberoi - Senior Consultant Hematology, Medanta, Gurgaon

#### **Speakers:**

1. Dr. B.S. Vivek – Senior Cardiologist at Sir Ganga Ram Hospital
2. Dr. Nikita Mehra – Hematologist & Oncologist, Chennai
3. Dr. Sanjay Kumar – HoD of Neurology, PMCH, Patna, Bihar

4. Dr. Sandeep Seth – Senior Cardiologist, AIIMS, New Delhi
5. Dr. Nikhil Kumar- Fortis Hospital

#### **IV. Neurological Challenges and Treatments in Amyloidosis**

Speaker: Dr. Sanjay Kumar, Head of Neurology, PMCH Patna

Case Studies: Dr. Kumar shared real-life experiences with amyloidosis patients, emphasizing his first encounter with a case involving small fiber neuropathy in 2008. He highlighted the insidious nature of the disease, often leading to delayed diagnosis.

Symptoms:

Common neurological symptoms include:

- Peripheral Neuropathy: Tingling, numbness, and loss of sensation.
- Autonomic Dysfunction: Issues with blood pressure regulation, digestion, and bladder control.
- Carpal Tunnel Syndrome: Often an early manifestation, caused by amyloid deposition in tendons.

Diagnostic Techniques:

- Polarized Microscopy: A gold standard for confirming amyloid deposits in tissue samples.
- Genetic Testing: Essential for hereditary amyloidosis cases.
- Electrodiagnostic Studies: Help assess nerve damage and muscle involvement.

Challenges in Treatment:

- Lack of disease-specific therapies for neurological amyloidosis.
- High dependence on supportive care, including pain management and physiotherapy.

#### **V. Cardiac Challenges in Amyloidosis**

Speaker: Dr. B.S. Vivek

Clinical Impact of Cardiac Amyloidosis:



- Amyloid deposits in the heart lead to stiffening of the myocardium, causing symptoms like fatigue, arrhythmias, and heart failure with preserved ejection fraction (HFpEF).
- The condition is often misdiagnosed as other forms of heart failure.

#### Diagnostic Approaches:

- Echocardiography: Detects thickened heart walls and reduced diastolic function.
- Biomarkers:
  - N-terminal pro b-type natriuretic peptide (NT-proBNP) to assess heart strain.
  - Troponin levels for myocardial damage.
- ECG Findings: Low-voltage QRS complexes often suggest amyloidosis.
- Advanced Imaging: Nuclear scans (e.g., bone scintigraphy) help confirm cardiac amyloid deposits.

#### Treatment Modalities:

- Chemotherapy Protocols: Combination regimens like VCD (bortezomib, cyclophosphamide, dexamethasone) are effective for light-chain amyloidosis.
- Stem Cell Transplantation: Offers potential cure for selected patients, particularly younger, healthier individuals.
- Supportive Care: Includes managing arrhythmias and heart failure symptoms.

Dr. Vivek concluded by urging improved access to diagnostic tools and therapies, noting that cardiac amyloidosis is often diagnosed at an advanced stage.

### III. Cardiac Amyloidosis Challenges and Innovations

**Speaker:** Dr. Sandeep Seth, Cardiologist, AIIMS, New Delhi

Dr. Sandeep Seth joined the discussion to provide specialized insights into the diagnosis and management of cardiac amyloidosis, a critical and often life-threatening manifestation of the disease.

#### Cardiac Manifestations of Amyloidosis

- Overview: Cardiac amyloidosis primarily results from amyloid deposits in the heart tissue, leading to myocardial stiffening and progressive heart failure. Dr. Seth described this condition as a silent disruptor, often misdiagnosed as hypertensive or restrictive cardiomyopathy.

- Prevalence: Highlighted that cardiac involvement is seen in most cases of AL (light chain) amyloidosis and transthyretin amyloidosis (ATTR), the latter being more common in older patients.

#### Diagnosis

#### Key Symptoms and Red Flags:

- Unexplained heart failure with preserved ejection fraction (HFpEF).
- Arrhythmias, including atrial fibrillation.
- Unusual signs, such as low-voltage QRS complexes on ECG and thickened ventricular walls on echocardiography without a history of hypertension.

#### Imaging Modalities:

- Cardiac MRI: Essential for detecting amyloid infiltration.
- Bone Scintigraphy/Nuclear Imaging: Used specifically to differentiate ATTR amyloidosis from other types.

Biomarkers: NT-proBNP and troponin levels are pivotal for identifying cardiac stress and damage, helping in prognosis.

#### Challenges in Diagnosis:

- Limited access to advanced imaging tools and nuclear scans, especially in rural areas.
- Lack of awareness among general practitioners, leading to delayed referrals.

#### Treatment Strategies:

- Dr. Seth elaborated on the evolution of treatments, particularly for ATTR amyloidosis, where new therapies target the stabilization or reduction of amyloid deposits:
- Tafamidis: A transthyretin stabilizer that slows disease progression in ATTR amyloidosis.
- Patisiran and Inotersen: RNA-based therapies that inhibit transthyretin production.

#### Light Chain Amyloidosis:

- Standard chemotherapy regimens, such as VCD (bortezomib, cyclophosphamide, dexamethasone), remain the mainstay for AL amyloidosis with cardiac involvement.
- Stem cell transplantation offers potential long-term remission but is only feasible for carefully selected patients due to the risks involved.

#### Supportive Care:

- Aggressive management of heart failure with diuretics and aldosterone antagonists.
- Control of arrhythmias with medications or device therapy (e.g., pacemakers).

#### Challenges in Care

- **Affordability:** Dr. Seth highlighted the high costs associated with new-generation drugs like Tafamidis and the limited insurance coverage for such treatments in India.
- **Infrastructure Gaps:** The need for specialized amyloidosis centers equipped with diagnostic tools like cardiac MRI and genetic testing labs was emphasized.
- **Delayed Diagnosis:** Late-stage diagnosis often leaves patients with fewer treatment options and poorer prognoses.

### **IV. Multisystem Involvement and Holistic Care**

Speaker: Dr. Nikhil Kumar

**Complexities in Amyloidosis:** Dr. Kumar referred to amyloidosis as a "disease in search of a doctor," explaining how its multi-organ involvement often leads to fragmented care.

#### Organ-Specific Symptoms:

- **Kidneys:** Proteinuria and nephrotic syndrome often lead to renal failure.
- **Liver:** Hepatomegaly and abnormal liver enzymes can mimic other liver conditions.
- **Gastrointestinal Tract:** Symptoms include malabsorption, diarrhea, and weight loss.

**Integrated Approach:** Advocated for a multidisciplinary team to manage amyloidosis, involving hematologists, cardiologists, neurologists, nephrologists, and gastroenterologists.

#### Treatment Insights:

- Discussed combination therapies like VCD and newer protocols targeting plasma cells.
- Described the role of immunomodulatory drugs and monoclonal antibodies in improving patient outcomes.

### **V. Mass Spectrometry and Research Advancements**

Speaker: Dr. Nikita Mehra, Physician Scientist

#### Mass Spectrometry as a Diagnostic Tool:

- Described as a breakthrough in non-invasive diagnostics, mass spectrometry can identify amyloid protein types directly from blood or urine samples.
- Benefits include reduced need for invasive bone marrow biopsies and the ability to monitor disease progression over time.
- Current studies involve validating this technique in large patient cohorts (3,500–4,000 participants).

#### Challenges in Amyloidosis Care:

- High cost of treatment: She highlighted daratumumab, a monoclonal antibody that has shown efficacy but remains unaffordable for many patients.
- Limited availability of advanced diagnostic equipment in rural and underserved regions.

#### Collaboration Opportunities:

- Shared insights from partnerships with international centers, including London and US-based institutes, to enhance research and treatment strategies in India.
- Advocated for "Make in India" initiatives to reduce the cost of amyloidosis drugs and diagnostics.

#### Future of Research:

- Emerging therapies such as anti-fibril agents, CAR-T cells, and bi-specific antibodies offer hope for more targeted treatment options.
- Research on reducing drug toxicity and improving access to generics is underway.

This expanded technical session captures the detailed discussions by the expert panel. Each speaker provided unique insights into their respective areas, underscoring the need for a holistic and multidisciplinary approach to tackling amyloidosis. Let me know if you'd like more depth on any specific topic!

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## 8. Q&A Panel

**8.1.Question:** *What can we expect in the next 5 years for amyloidosis treatment and diagnosis?*

**Response:** Advancements in diagnostic techniques like cytogenetic testing, polarized microscopy, and mass spectrometry are anticipated. Holistic medicine approaches and improved prognostic tools, such as cardiac markers, are also being developed to enhance patient outcomes.

**8.2.Question:** *Will this initiative also address genetic causes of amyloidosis or only acquired causes?*

**Response:** Both genetic and acquired amyloidosis will be included. Genetic causes like fibrinogen mutation-related amyloidosis and secondary causes (e.g., TB, rheumatoid arthritis) will be considered in patient care and support.

**8.3.Question:** *What are the costs and efficiency of treatment options like CAR-T cell therapy?*

**Response:** CAR-T cell therapy is still in the research phase and not widely available. Treatments like autologous stem cell transplants, although effective, remain expensive. Efforts are underway to develop cost-effective alternatives, including local generics.

**8.4.**

**Response:** While the FLC ratio is critical, trends over time, rather than single values, provide more insights. A rise in both kappa and lambda chains with a stable ratio often indicates an infection rather than disease progression.

**8.5.Question:** *What can be done for macular amyloidosis on the skin?*

**Response:** Macular amyloidosis, characterized by localized skin patches, often requires topical treatments and monitoring for associated conditions. Multidisciplinary care may be needed if systemic involvement is suspected.

**8.6.Question:** *What is the protocol for abdominal fat pad biopsy?*

**Response:** Abdominal fat pad biopsy, a minimally invasive diagnostic method, typically involves aspirating 1-2 microns of tissue. Sensitivity is around 85%-90%, making it a first-line diagnostic tool.

**8.7.Question:** *Is it normal for FLC numbers to fluctuate post-transplant?*

**Response:** FLC fluctuations can result from immune reconstitution post-transplant.

Monitoring trends, organ function, and related parameters is essential to differentiate between normal immune responses and disease progression.

**8.8.Question:** *What options are available for patients unable to afford advanced treatments?*

**Response:** Alternative treatment regimens, including cyclophosphamide and dexamethasone, can be effective. Efforts to lower drug costs and government support for rare diseases are critical for broader access.

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## **9. Concluding Remarks**

**Speaker: Dr. Gurleen Oberoi**

Conclusion: Dr. Gurleen Oberoi wrapped up the session by emphasizing the need for continued collaboration between clinicians, scientists, and patients to improve the diagnosis, treatment, and overall care for amyloidosis patients.

She expressed hope that the research on mass spectrometry and the development of affordable therapies would lead to better patient outcomes in the future.

**Speaker: Dr. Satish Chandra**

Dr. Chandra concluded the session with a heartfelt thank you to all participants, speakers, and attendees. He acknowledged the generous donation of ₹5 crores towards the cause and expressed his commitment to improving the care landscape for amyloidosis patients across India.

Future Plans: Dr. Chandra mentioned that ASGI would continue to work towards building more chapters across the country and increasing awareness about amyloidosis.

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## **10. Challenges and Solutions Identified**

### **10.1. Concern Raised**

- Limited access to diagnostic tools and specialized tests in rural areas.
- High treatment costs, particularly for advanced therapies.
- Lack of widespread awareness among healthcare providers.

## **10.2. Proposed Solutions**

- Increased awareness and education among healthcare providers and the public.
  - Policy advocacy to include rare diseases like amyloidosis in national health programs.
  - Financial assistance programs and insurance coverage to alleviate the burden on patients.
  - Establishing a national patient registry and dedicated amyloidosis care centers to enhance infrastructure and treatment accessibility.
  - Collaborations to drive local innovation, research, and cost-effective solutions
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## **11. Future plans:**

- Bihar Amyloidosis Centre: Initiative and plan for the development of the ASGI Bihar Centre
  - Continuation of Regional Project (36 Chapters) : Strategies to making all 36 chapters of ASGI ( 28 States + 8 Union Territories of India) functional by the end of 2025. Starting with Bihar, followed by West Bengal Chapter.
  - Technology Integration : Proposal for National amyloidosis patient portal, patient data-base, amyloidosis tracking and management apps.
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## **12. Media Coverage and Social Media Engagement**

The event was publicized through social media and received notable engagement, with quotes from experts shared widely. Patient testimonies further amplified the event's message, with media attention on ASGI's advocacy efforts and policy proposals.

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## **13. Conclusion**

The World Amyloidosis Day webinar proved a pivotal platform for raising awareness and discussing actionable solutions for amyloidosis care.

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## **14. Webinar planning & execution Summary**

## **Report on Services Rendered for ASGI Webinar on Amyloidosis Bihar Chapter (3<sup>rd</sup> December 2024)**

This report outlines the scope of services provided by Vizve Design for the “Unveiling Amyloidosis: Bihar Chapter” webinar, organized by ASGI and RDSSDF 3<sup>rd</sup> December 2024. The report provides an account of the tasks executed, promotional efforts, technical support, and post-webinar activities, in accordance with the terms set out in the Memorandum of Understanding (MoU) between Vizve Design and ASGI.

### **Detailed Work Summary**

#### **14.1. Pre Promotional Content Development**

14.1.1. **Initial Promotional Post:** Created and disseminated the first promotional post in English & Hindi language. Which has been shared across all social media platforms to generate awareness of the upcoming event.

14.1.2. **Invitation Flyer:** Created and disseminated the flyer in English & Hindi language. Which has been shared through email, WhatsApp.

14.1.3. **Webinar Banners:** Produced Hindi & English banners for the RDSSDF and ASGI websites.

14.1.4. **Reminder Card Design:** Developed reminder card in Hindi & English.

#### **19.2. Post-Webinar Promotional Content Development:**

19.2.1. **Social media Post :** Produced a two-page post in Hindi & English to commemorate the success of the webinar.

- Success post
- Highlights of the event flow Post

#### **19.2.2. Webinar Promotion on website:**

- Website banner: Created website banners for both RDSSDF and ASGI, featuring a clickable link to the webinar report (PDF format).



- Integrated a popup on the websites containing additional details about the webinar report.
- Uploaded the PDF report to the education section of the website.

### **19.3. YouTube Video:**

Developed a video of 3 hours to document the live conversation and to share on YouTube

### **19.4. Webinar Platform Setup:**

Generated a Google Meet link supporting up to 150 participants.

### **19.5. Technical Support Provision:**

Oversaw the technical setup, monitored the smooth functioning of the platform during the webinar, resolved technical issues for attendees, and facilitated screen sharing, presentations, and other live support to ensure a seamless event experience.

### **19.6. Event Planning, Moderation, and Execution:**

Organized and structured the event flow, curated content, and moderated the webinar to achieve efficient execution.

Developing a document & a excell to be followed by the event coordinator

### **19.7. Coordination and Outreach:**

Conducted extensive outreach efforts as follows:

- Sent over 2,500 emails to doctors and patients globally.
- Disseminated WhatsApp messages to 200 individuals.
- Made individual phone calls to 150 participants.
- Reach out to 150 media personal via WhatsApp & email.
- Gathered email ID of various international organization.
- A separate PDF listing all contacted individuals will be shared.

### **19.8. Question Collection and Q&A Compilation:**

Compiled and categorized Q&A topics submitted by patients, which were subsequently integrated into a presentation shared with the panel of doctors to facilitate discussion during the session. The FAQ document was uploaded to the learning section on the ASGI portal.

**19.9. Full documentation of the event in details:**

Post-event generating a detailed report on attendee engagement, minutes of the meeting along with uploading all knowledge materials to the ASGI website

**19.10. Additional Responsibilities as per the MoU:**

In alignment with the MoU, Vizve Design was responsible for webinar platform selection, coordination with ASGI, comprehensive event organization, and content management

**19.11. Duration of Engagement**

The MoU was effective from 21st October 2024 to 10th November 2024.

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**20. Appendices**

- **Event Photos and Media:** Images & video capturing key moments from the webinar.
  - **Full Transcript:** Document of discussions and presentations.
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