Issue No. 53

Thalassemics India Newsletter

AUG -DEC 2025

Thalassemics India Conducts 37th Annual General Meeting

Thalassemics India successfully held its 37th Annual General Meeting on 23rd November 2025 at the Constitution Club, New Delhi, with over 120 patients and parents in attendance.
The President, Mr. Deepak Chopra, welcomed members, and the event began with a heartfelt Ganesh Vandana by five thalassemics. Dr. Seema Kapoor, Director, CNBC & Delhi State Blood Cell, shared insights on key government initiatives for thalassemia care.

The Financial and Secretary's Reports were presented by Mr. Arun Sehgal and Mrs. Shobha Tuli, respectively. Mr. Viresh from TPAG highlighted achievements and encouraged youth participation.
Under the Helping Hands Project, 14 patients received chelation medicines and leukocyte filters. The meeting concluded with a warm lunch and community interaction

Helping Hands Project

During the quarter Aug- Dec 2025, Thalassemics India extended support to 127 thalassemia patients undergoing treatment at leading government and private hospitals, including Hindu Rao Hospital, Kasturba Hospital, All India Institute of Medical Sciences, Safdarjung Hospital, Lady Hardinge Medical College, Charak Palika Hospital, and St. Stephen's Hospital.

This support ensured continuity of care, timely treatment, and access to essential medical services for patients from diverse and underserved backgrounds. Through close coordination with hospital teams and stakeholders, Thalassemics India remains committed to strengthening thalassemia care and improving the quality of life for patients and their families.

Medicial/ Equipment	Qty.	Amount (in Rs.)
Desirox 500 Mg	450 boxes	427500
Bio r double unit filter	431 pcs	555128
Defrijet FCT 360 Mg	344 boxes	187136
Desferal Injections	280 boxes	611723
Kelfer 500 Mg	249 boxes	127488
Imugard single unit filter	118 pcs	115640
Defrijet 500 Mg	98 boxes	71540
		2096155

Driving Early Detection: Thalassemia Screening Initiatives

Thalassemics India continues to strengthen its prevention efforts by coordinating multiple screening camps in collaboration with the Indian Red Cross Society and Rotary Club of Delhi, Safdarjung.

During this period, several screening camps were successfully conducted across institutions and community venues, reinforcing our commitment to early detection and prevention of thalassemia. Through sustained awareness initiatives, preventive screening, and collaborative action, Thalassemics India remains steadfast in its mission to reduce the burden of thalassemia.

All 4,039 collected samples were sent to the Thalassemia Screening & Counselling Centre, Indian Red Cross Society, New Delhi, for CBC and HPLC testing. Out of the tested samples, 3.96% are identified as having the thalassemia trait.

Blood donation and screening camps were conducted at the following places:

1. **18 Sept 2025 –** Maitreyi College, Chanakyapuri, New Delhi
2. **19 Sept 2025 –** Kamkus College of Law, Ghaziabad
3. **21 Sept 2025 –** Hotel Delight Grand
4. **30 Oct 2025 –** Shaheed Bhagat Singh College, New Delhi
5. **06 Nov 2025 –** DAV Centenary College, Faridabad, Haryana
6. **08 Nov 2025 –** Maitreyi College, Chanakyapuri, New Delhi
7. **10 Nov 2025 –** Maitreyi College, Chanakyapuri, New Delhi
8. **30 Nov 2025 –** Grand Utsav Banquet

Red Cross society

To Organize Blood Donation and Screening Camps:
please contact Thalassemics india at email: **thalcind@yahoo.co.in**
Tel: 011-41827334 / 46595811

Strengthening Blood Safety

NAT services have been successfully restarted with effect from 6th October 2025 at the Indian Red Cross Society Blood Bank, National Headquarters, New Delhi, through the joint efforts of Thalassemics India and a corporate donor. We sincerely thank the donor for their generous support, which will significantly enhance blood safety for patients with thalassemia major.
NAT tested blood units are being provided to thalassemia major patients completely free of cost.

- **October 2025: 683 units**
- **November 2025: 991 units**
- **December 2025: 1,024 units**

Thalassemia Bal Sewa Yojana (TBSY)

Thalassemia Bal Sewa Yojana (TBSY): A CSR initiative of Coal India Limited under the auspices of the Ministry of Health & and Family Welfare, Government of India.

The Coal India CSR-funded Hematopoietic Stem Cell Transplant (HSCT) program is a unique initiative aimed at providing a one-time cure opportunity to underprivileged thalassemia patients who have a matched sibling or matched unrelated donor but do not have the financial resources to cover the cost of the procedure. Aplastic anemia patients are also covered under this program. Under TBSY, 915 thalassemia and aplastic anemia patients have undergone successful Bone Marrow Transplant at the 17 empanelled hospitals across the country.

Image for representation purpose only

S. No	Name of the Hospital	
01	Narayana Hrudalaya, Bengaluru	235
02	CMC, Vellore	222
03	RGCIRC, New Delhi	190
04	Kokilaben Dhirubhai Ambani, Mumbai	75
05	Bhagwan Mahaveer Jain Hospital, Bengaluru500 Mg	33
06	MCGM, Mumbai	29
07	Tata Medical Centre, Kolkata	27
08	CMC, Ludhiana	26
09	Fortis Foundation, New Delhi	25
10	AIIMS, New Delhi	16
11	Indraprastha Apollo Hospitals, Delhi	14
12	PGIMER, Chandigarh	12
13	SGPGI, Lucknow	06
14	Medanta Foundation, Delhi	03
15	ASTER DM Foundation, Bengaluru	02
	Total	**915**

Thal MSD/MRD : 773
AA : 76
Thal MUD : 66

Male : 603
Female : 312

S. No	Name of the State	Total
01	Maharashtra	124
02	Uttar Pradesh	115
03	Karnataka	99
04	Bihar	81
05	Madhya Pradesh	78
06	Jharkhand	55
07	Haryana	50
08	Punjab	47
09	Andhra Pradesh	46
10	West Bengal	42
11	Delhi	38
12	Chattisgarh	25
13	Kerala	23
14	Odisha	17
15	Telangana	17
16	Gujrat	14
17	Rajasthan	12
18	Tamil Nadu	12
19	Assam	9
20	Himachal	5
21	Uttarakhand	2
22	Arunachal Pradesh	1
23	Dadar & Nagar Haveli	1
24	Goa	1
25	Jammu & Kashmir	1
	Total	**915**

Cumulative report - State wise (till 31st December, 2025)

Four Hospitals Have Been Newly Empanelled By The Ministry Of Health & Family Welfare, Govt. Of India, Under The Thalassemia Bal Sewa Yojana Project

Kamalnayan Bajaj Hospital, Aurangabad

Rainbow Children's Hospital, Hyderabad

SEAIT, Jaipur

Apollo Speciality Hospital, Chennai

Spreading Smiles

EVENT 1: Thalassemics India sincerely thanks Team ICREON for their generous and thoughtful celebration held on 21 December 2025 at our office.

The team spent joyful moments with the children, playing games and distributing gifts, spreading smiles and festive cheer all around. We are truly grateful for their continued support and encouragement in bringing happiness to our thalassemics.

EVENT 2: Another celebration with children to welcome the New Year.

EVENT 3: Thalassemics India celebrated the onset of the New Year at Pizza Hut, Connaught Place on 27th December.

Philanthropic Friends

We gratefully acknowledge the individuals and organizations who have generously contributed to our cause during this period. Thalassemics India extends its heartfelt thanks to every donor. Your support strengthens our mission and adds renewed hope and healing to the lives of children and families we serve.

- Pooja Nangia
- Shobha Marwah
- Bansal Neeraj & Associates
- Ravinder Ghai
- Brindavan Agro Industries Pvt. Ltd.
- Lions Service Foundation

New Members

Adult thalassemics and parents/guardians of children diagnosed with thalassemia are registered as beneficiaries. A one-time subscription fee of ₹2,000 is paid by each beneficiary at the time of registration.

Md. Irfan	Delhi
Rani Anuragi	Delhi
Hetal Rajesh Bhuta	Delhi
Noor Mohammed	Delhi
Divya Nagpal	Delhi
Narendra Nath Kundu	Delhi
Harish Soni	Uttar Pradesh
Ashok Sharma	Uttar Pradesh
Aakash Yadav	Uttar Pradesh
Suraj Rajbhar	Uttar Pradesh
Aarti Madan	Rajasthan
Lalu Joshi	Maharashtra
Sharik Sajid Langha	Maharashtra
Rajjakh Shaikh	Maharashtra
Sangeeta Goswami	Madhya Pradesh
Varun Kumar	Bihar
Rajesh Singh Tomar	Bihar

Thalassaemia International Federation

The Annual General Assembly (GA) was held virtually on Wednesday, 17 December 2025, in line with the Federation's constitutional commitments.

The Assembly brought together members from across the globe to review the Federation's progress and collectively shape the future direction of its global work.

Key Highlights of the Meeting:

- Review and approval of TIF's Annual Activity Report (2024 – October 2025)
- Presentation and adoption of the Audited Financial Accounts for 2024
- Outline of Strategic and Operational Priorities for 2026
- Updates on the next General Assembly, Board Member Elections, and TIF's International Conference 2027

The session reflected strong global collaboration and a shared commitment to advancing thalassemia care worldwide.

Impactful Collaborations

Improving Access to Care for Haemoglobinopathies – A high-level roundtable discussion was held on 22 August 2025 at the India Habitat Centre, New Delhi. The event was organised by Chase Advisors.

The keynote address was delivered by Dr. Vinod Kumar Paul, Member, NITI Aayog, Government of India. The session was chaired and moderated by Dr. Shubnum Singh, Principal Advisor – Healthcare, Confederation of Indian Industry (CII).

The roundtable brought together leading experts and community representatives, including Dr. Tulika Seth, Dr. K. Madan Gopal, Dr. Mohit Choudhary, Dr. Giriraj Ratan Chandok, Shobha Tuli, Gautam Dongre, Henna Dhawan, and others, fostering meaningful dialogue on strengthening access, policy support, and patient care for haemoglobinopathies.

Awareness Initiative by Rotary District 3011

In a bold and innovative move, Rotary District 3011 has taken thalassemia awareness beyond conference halls and into the heart of public life — the Swarn Shatabdi and Vande Bharat trains. By transforming everyday travel into an opportunity for education, this initiative is reaching thousands of passengers with a message that truly matters.

Thalassemics India wholeheartedly commends District Governor Ravi Gugnani and his dedicated team for leading this high-impact campaign. Such visionary outreach not only spreads awareness but also strengthens the collective resolve to prevent thalassemia and build a healthier future.

Fundraising Carnival – A Celebration With A Cause

A Fundraising Carnival organised by the Rotary Club of Delhi Premier (RCDP), District 3011, was held on 6–7 December 2025 at Select Citywalk, Saket, New Delhi, in aid of Thalassemics India.

This vibrant event featured:

- Live band and music
- Quiz competitions
- Nukkad Nataks
- Performances by school students
- Over 40 stalls offering food, artefacts, and handmade articles

The presence of the RCDP Board and the Hon'ble District Governor, along with our thalassemics, made this initiative exceptionally impactful in spreading awareness about thalassemia. We extend our heartfelt gratitude to RCDP for this inspiring initiative.

ECHO Webinars – Advances in Thalassemia Care

Prof. Dimitrios Farmakis
(TIF)

The 6th ECHO Webinar on the Advances in Thalassemia Care series was held on 13 November 2025. The webinar series was organised by Postgraduate Institute of Child Health (PGICH) in collaboration with Thalassaemia International Federation (TIF) and Thalassemics India under the banner of ECHO India. With over 140 participants from India and overseas, the session focused on cardiac complications in thalassemia.

Distinguished Speakers:

- **Prof. Dimitrios Farmakis (TIF)**
- **Dr. Neeraj Aggarwal**
- **Dr. Anuj Sharma, Pediatric Cardiologist**

The panel discussions, moderated by Dr. Nita Radhakrishnan, addressed real-world management challenges, while Mr. Deepak Chopra & Mrs. Shobha Tuli highlighted the patient advocacy perspective and national efforts to strengthen thalassemia care.

Webinar Series on Advances in Thalassaemia Care

Session 6: Cardiac Morbidity in Thalassemia – Prevention and Treatment

Thursday,
13th November 2025

6:00 PM -8:00 PM (IST)
12:30 PM -2:30 PM (GMT)

Chairperson	Context Setting	Speaker	Speaker	Speaker	Moderator
Dr Androulla Eleftheriou	**Mrs. Shobha Tuli**	**Prof. Dimitrios Farmakis**	**Dr. Neeraj Aggarwal**	**Dr. Anuj Sharma**	**Dr. Nita Radhakrishnan**
Executive Director, Thalassaemia International Federation	Secretary, Thalassemics India, President, Federation of Indian Thalassemics	Professor of Cardiology, National and Kapodistrian University of Athens, Greece	Director, Pediatric Cardiology, Sir Ganga Ram Hospital, New Delhi	Asst. Professor, Department of Pediatric Cardiology, PGICH Noida	Additional Prof. & HOD, Pediatric Hematology Oncology, PGICH Noida

REGISTER NOW

Webinar Series on Advances in Thalassaemia Care

Session 7: Bone Pain in Thalassemia: Why, When, Prevention and Treatment

Friday,
19th December 2025

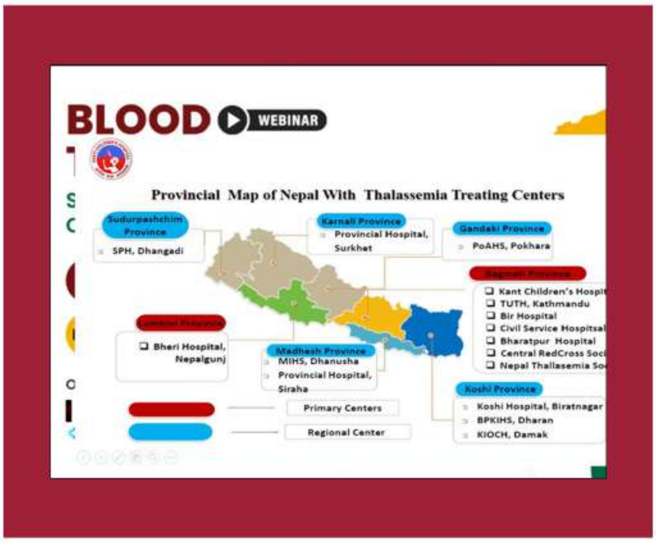
6:00 PM -8:00 PM (IST)
12:30 PM -2:30 PM (GMT)

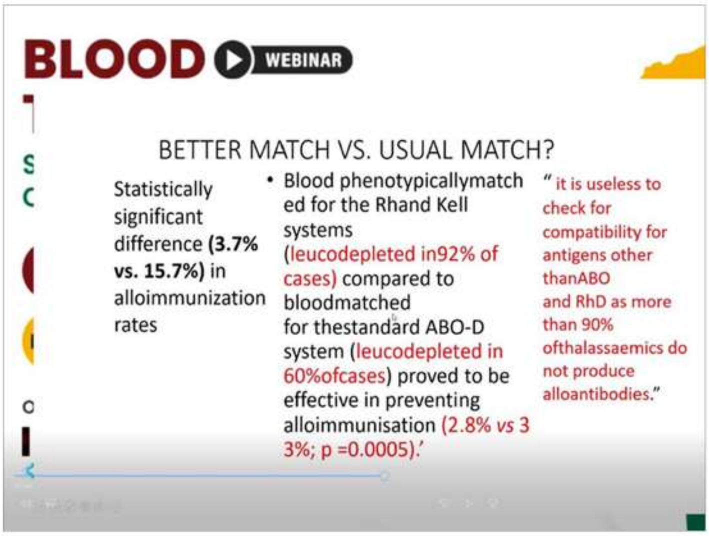
Chairperson	Context Setting	Speaker	Speaker	Case Presenter	Moderator
Dr. Androulla Eleftheriou	**Mr. Deepak Chopra**	**Dr. Maurizio Poggi**	**Dr. Anju Seth**	**Dr. Sudipto Bhattacharya**	**Dr. Nita Radhakrishnan**
Executive Director, Thalassemia International Federation	President, Thalassemics India	Professor and Chair, Endocrinology , Sant'Andrea Hospital, Rome, Italy	Director Professor, Department of Pediatrics & Principal, Lady Hardinge Medical College-New Delhi	2nd Year Fellow, Pediatric Hematology Oncology, PGICH, Noida	Additional Prof and Head, Pediatric Hematology Oncology, PGICH, Noida

REGISTER NOW

The Thalassaemia International Federation (TIF) in collaboration with the Indian Subcontinent Network for Haemoglobin Disorders (ISNHD) organised a webinar on Blood Transfusion Safety, Availability & Challenges in the Indian Subcontinent.

This regional webinar brought together leading experts from Bangladesh, India, the Maldives, Nepal, Pakistan, and Sri Lanka to discuss pressing issues around blood transfusion safety, access, and innovation. Participants gained valuable insights into national perspectives, regional challenges, and collaborative strategies to strengthen transfusion systems across South Asia.





BETTER MATCH VS. USUAL MATCH?

Statistically significant difference **(3.7% vs. 15.7%)** in alloimmunization rates

- Blood phenotypicallymatched for the Rhand Kell systems (leucodepleted in92% of cases) compared to bloodmatched for thestandard ABO-D system (leucodepleted in 60%ofcases) proved to be effective in preventing alloimmunisation (2.8% *vs* 3 3%; p =0.0005).'

" it is useless to check for compatibility for antigens other thanABO and RhD as more than 90% ofthalassaemics do not produce alloantibodies."

TRANSMEDCON 2025

On behalf of the patient community, Thalassemics India would like to thank the organising committee of TRANSMEDCON 2025 for inviting a non-medical person to speak on "Recent initiatives on the management of thalassemia in India- an NGO perspective".
Our Secretary Mrs Shobha Tuli felt privileged to be invited to this meeting.

She appealed to the ISBT & ISTM to look at :-

1. Anaemia and low haemoglobin with regard to low participation of female blood donors
2. Availability of blood without replacement
3. Blood safety

Hope for a Healthier Tomorrow – Kolkata

Hope for a Healthier Tomorrow, an awareness event, was successfully held on 21st December at Narayana RN Tagore Hospital, Kolkata. The programme was graced by the presence of senior officials from Coal India Limited, Shri Vinay Ranjan Ji and Shri O.P. Mishra Ji.
An informative overview of the Thalassemia Bal Sewa Yojana was presented by Dr. Sunil Bhat, highlighting the scheme's objectives and benefits for thalassemia-affected children and their families.
The event also saw the participation of several esteemed dignitaries, including Madam Renu Chaturvedi, Mrs. Shobha Tuli, Dr. Sudipa Chakravarty, Mr. Apurba Ghosh, along with representatives from various voluntary organizations across West Bengal.
Thalassemics India sincerely thank Narayana RN Tagore Hospital for organizing the programme and DKMS for offering free HLA testing, a crucial step towards potential curative treatment & giving us an opportunity to be part of this event.
A HLA camp was also held at the venue attended by more than 300 people including thalassemia patients & their families.


Pooja Khurana

"Believe in yourself. Your diagnosis does not define your destiny"

Pooja Khurana, *a 43-year-old Thalassemia Major warrior from Delhi, is a published anthology writer, social worker, and Assistant Manager at an IT company.*

In a heartfelt and empowering conversation with ***Sonam Madan****—also herself a Thalassaemic, long-time advocate, and active contributor to Thalassemics India—Pooja shares her journey of resilience, creativity, and unwavering self-belief.*

Her story is not just inspiring; it is a beacon of hope for everyone navigating life beyond a diagnosis. Together, they speak about resilience, purpose, and the power of community in shaping meaningful lives.

Sonam: You work as an Assistant Manager in a reputed IT company and are also an anthology writer. What keeps you going?

Pooja:

I was motivated to become a writer largely because of my father. He was an avid reader, and growing up, reading was a big part of our daily life. That habit naturally sparked my curiosity for stories and language. Over time, reading evolved into writing— it felt like a natural extension of the passion we shared. Writing became not just a hobby, but a way for me to express ideas, reflect on experiences, and connect with others. It gives me purpose and keeps me inspired.

Sonam: You completed your Master's and B.Ed. and even taught at a special school. How was that experience?

Pooja:

Yes, during my Master's and B.Ed., I had the opportunity to teach at a special school, and it was truly transformative. Working with children who had diverse learning needs taught me patience, empathy, and the importance of individualized teaching methods. It made me more observant and adaptable. Every small achievement by a student felt incredibly rewarding. That experience deepened my understanding of inclusive education and continues to influence my approach to both teaching and writing.

Sonam: How would you describe your writing?

Pooja:

I'm an anthology writer with a deep passion for short stories. I've always been drawn to the power of concise storytelling and the way it can leave a lasting impact. Over the years, my work has been published and recognized both nationally and internationally, which has been incredibly fulfilling. Being part of various anthologies has allowed me to collaborate with talented writers and explore diverse themes and styles.

Sonam: Living with thalassemia can be challenging. What has worked well for you?

Pooja:

I feel incredibly blessed to have had unwavering support throughout my journey. My parents laid the foundation by nurturing my love for reading and learning from a young age. I've been fortunate to have mentors and bosses who believed in my potential and gave me the space to grow professionally. My husband has been more like a friend. His constant encouragement has helped me take bold steps, especially in my writing. And perhaps one of the most touching blessings has been the toddlers I used to teach. Their innocence, curiosity, and unconditional affection taught me more about patience, joy, and purpose than I could ever put into words.

Sonam: Besides writing, what else do you like to doing?

Pooja:

I love cooking and dancing but with my weak bones I am not allowed to dance much. I like attending poetry sessions. I have been a part of Habitat Centre's poetry sessions.

Writing was always there in my DNA which deciphered into 10+ anthologies.

> “Whether it's your physical health or mental well-being, asking for support is a strength, not a weakness.

Sonam: What message would you like to give to the younger Thalassemics?

Pooja:

Surrender to the universe but never hesitate to seek help —wherever and whenever it's needed. Whether it's your physical health or mental well-being, asking for support is a strength, not a weakness. Let 'Love Thyself' be your guiding motto. Because true strength begins with self-compassion.

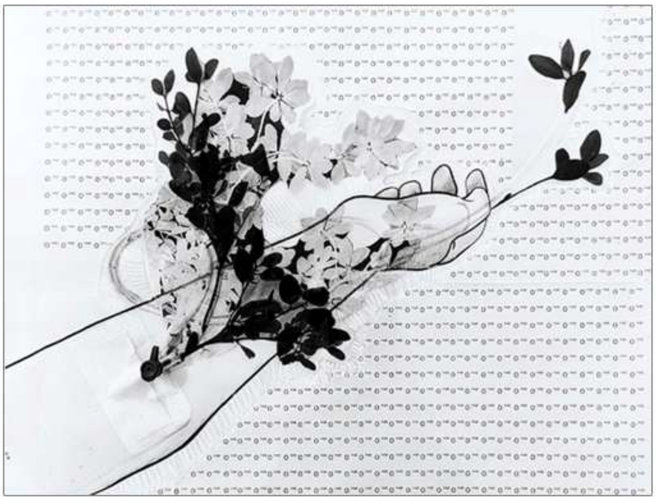
> ***"Through this body of work, my aim is to spread awareness about Thalassemia as a disorder and to explore how a chronic illness deeply affects an individual."***
>
> **- Rahul Wahi**

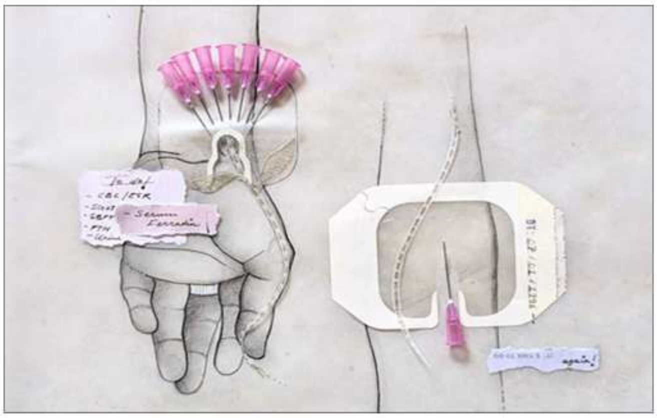
I am a visual artist based in Delhi. My current creative process is a direct response to my lived experience as a Thalassemia Major patient—a journey that has profoundly shaped my identity, perceptions, and artistic sensibilities.

Through my work, I seek to navigate the intricate relationship between my disability and identity, examining how Thalassemia has both challenged and expanded my creative potential. Through this body of work, my aim is to spread awareness about Thalassemia as a disorder and to explore how a chronic illness deeply affects an individual.

Central to my practice is the use of photographic prints from images I capture, which I deconstruct, cut, and reassemble. I use gateway sheets as my base surface because they provide a sense of sensitivity and transparency to my work, revealing multiple layers that are metaphorically similar to life itself—unfolding in overlapping layers of emotion. My current focus on a monochromatic palette allows me to explore tonal variations, contrasts, and layered transparencies, creating depth and movement within my compositions. Figuration plays a crucial role in my work, enabling me to articulate gestures and narratives while challenging conventional representations of the body and its fragility.

I approach my art as an evolving dialogue one that thrives on spontaneity, materiality, and the interplay of memory and form. By recontextualizing objects and images within my compositions, I aim to imbue them with new dimensions of meaning and vitality, encouraging viewers to engage with the work on an introspective level. My practice is inspired by the ever-shifting nature of human existence—both physical and emotional reflecting on transformation, resilience, and the fluid boundaries between personal and collective experiences.





Thalassemics India

Visit Our Website: www.thalassemicsindia.org

DONATE TO SUPPORT LIVES WITH THALASSEMIA

Stand with patients battling Thalassemia every single day.
Your contribution helps provide safe blood transfusions, essential medicines, iron chelation therapy, and access to life-saving treatments.

YOUR GIFT CAN GIVE HOPE. YOUR SUPPORT CAN SAVE LIVES.

Together, we can ensure that no child or adult with Thalassemia is denied the care they deserve.

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Thalassemics
India