MUKTA.

Mission to Unite & Keep Thalassemia Away

Master Trainer Session

21st August, 2025
The Westin, Pune

FEDERATION OF OBSTETRIC AND GYNAECOLOGICAL SOCIETIES OF INDIA FOGSI

Ek Rashtra - Ek Mission
Swastha Nari - Samruddha Vatan
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Project MUKTA

India is the Thalassemia capital of the world. Every year, India adds 10,000 - 15,000 Thallasemia Major patients, a condition which is difficult to manage and treat and relatively much easier to prevent.

To take decisive action on this issue, FOGSI has partnered with Veha Foundation to launch Project MUKTA, which is an initiative aimed at integrating Thalassemia screening and prevention into routine antenatal care across India.

The day began with an address from Dr Sunita Tandulwadkar, President, FOGSI followed by a launch of the GCPR and addresses by Dr Jaydeep Tank, Immediate Past President, FOGSI, Rumana Hamied, Director, Veha Foundation and Dr Bhaskar Pal, President Elect, FOGSI. Dr Pooja Lodha, National Convenor, Project MUKTA and Dr Manoj Pal, Joint Project Director, Project MUKTA also addressed everyone.

After that, attendees split into three groups to discuss technical materials. They made notes and suggestions which they then presented to the large group one by one.

"Ten years ago, people asked if cervical cancer vaccination was feasible - now it's routine. Thalassemia screening must follow the same path"

"Thalassemia intervention cannot be limited to the private sector. It has to involve the government, MPs, and MLAs - otherwise the impact will stay small."

Group 1 emphasized the critical role of early counselling alongside prenatal diagnostic testing, and highlighted the need for clear, stigma-free communication around carrier status. They discussed broadening screening beyond high-risk groups, drawing lessons from global practices, and stressed youth-focused awareness campaigns using influencers and creative materials. Key decisions included standardising terminology (“carrier” vs. “positive/negative”), ensuring accurate reporting even in cases of severe anaemia, and prioritizing accessible outreach tools for both doctors and the public.

GROUP 2

HPLC and Genetic Testing

"We should not lose any opportunity - whether at adolescence, preconception, or during pregnancy - to define a woman's Thalassemia status. This has to become part of a life-course approach."

"We strongly advocate for state-sponsored HPLC testing in coordination with professional bodies' leadership - this will ensure uniformity, reduce costs, and expand access."

The second group, which deliberated on the HPLC & Genetic Testing section of the training module, provided several critical recommendations to strengthen both technical protocols and patient communication. They called for SOPs to address false negatives in severely anemic women and referrals to genetic counselors or labs when atypical peaks appear with elevated HbA2/HbF. A module on hemoglobinopathy counseling and a life-course approach to women's testing were proposed. To reduce stigma, members suggested framing screening as a "Family Wellness Drive" and using "carrier" instead of "Thalassemia positive." Policy recommendations included a national Thalassemia registry and state-sponsored HPLC testing. They also stressed counseling women that HPLC is a once-in-a-lifetime test.

"The cost of prevention through screening and counselling is less than 1% of the annual treatment cost of a thalassemia major child."

"At minimum, the pregnant woman must be screened, but ideally both partners should be tested."

"Iron deficiency can mask thalassemia carrier status by lowering HbA2—ferritin testing is essential in parallel. An HPLC test should be delayed by 2 weeks after iron supplementation and 3 months after blood transfusion."

"Molecular testing is indispensable for ambiguous cases and prenatal diagnosis, focusing on common mutations to control costs."

The third group convened to examine FAQs on Thalassemia in India. There was a keen focus on prevalence data, screening protocols, economic implications, and policy considerations. The group debated universal versus targeted screening approaches, highlighted the importance of early antenatal and couple screening, and reflected on cultural and social barriers that influence timelines and acceptance. Protocols for testing were emphasized, including the need to refer a patient for HPLC at least three months after a blood transfusion and two weeks after iron supplementation to avoid misinterpretation. Practical guidance for practitioners, cost-benefit insights, and implementation challenges were also deliberated, alongside the need for clearer national guidelines, structured protocols, and effective project planning to strengthen thalassemia prevention strategies.

After the group discussions and presentations, the attendees expressed their commitment to the cause by signing the pledge wall, affirming their collective vision of a Thalassemia-free India. They also participated in creating short promotional reels to raise awareness on screening, carrying the powerful motto *"HPLC for all, Thalassemia for none."*

There was also a press conference where the GCPR for Universal Antenatal Thalassemia Screening was released and members of the press were briefed by FOGSI leadership.

The day ended with a heartfelt vote of thanks from Dr Sunita Tandulwadkar, President, FOGSI and presentation of mementos to Dr Sunita Tandulwadkar, President, FOGSI, Dr Jaydeep Tank, Immediate Past President, FOGSI, Dr Bhaskar Pal, President Elect, FOGSI, Dr Pooja Lodha, National Convenor, Project MUKTA and Rumana Hamied, Director, Veha Foundation.