



# Importance of Blood Donation and Managing Wellness of People with Thalassemia

## Illness to Wellness

July 2021



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## ***Thank you....***

We extend our deepest gratitude for the individuals that contribute to the health of our community and have invested their life in caring for others. Amidst this pandemic our frontline workers are the true heroes, leading the relentless fight to keep us safe.



## Importance of Blood Donation and Managing Wellness of People with Thalassemia

ASSOCHAM Foundation for Corporate Social Responsibility (AFCSR) launched a national awareness programme, 'Illness to Wellness', to promote healthy living in association with SAVLON. The series aimed to educate people across India and abroad about various health-related matters, especially amidst the COVID-19 pandemic. In addition, various experts were invited to share insights on precautions, treatments, and related issues.

On the occasion of International Day of Persons with Disabilities, a webinar was conducted by AFCSR on the topic

**'Importance of Blood Donation and Managing Wellness of People with Thalassemia'.** Expert panelists deliberated issues such as blood supply before and during COVID-19, the role of various holders during this time, other aspects of thalassemia management, including the learning from the pandemic, and the overall situation of blood supply and management against the RPWD Act 2016.

Thalassemia is a hereditary blood disorder wherein the human body produces less haemoglobin than normal.<sup>1</sup> This condition leads to severe anaemia, tiredness, fatigue, and growth failure. Therefore, patients require lifelong blood

transfusions every 2-3 weeks to survive. This requirement may vary once the age progresses, and the patient grows.



Further, due to repeated transfusions, the patient may have iron overload, which can cause damage to the vital organs in case it is not appropriately treated.<sup>2</sup> Iron chelation therapy is used to remove excess iron in these patients. A blood and marrow stem cell transplant are the only cure available for patients with this disability.<sup>3</sup> Bone Marrow Transplantation (BMT) is a complicated and expensive procedure. These patients are also at risk of contracting a blood-related disease.<sup>4</sup> Therefore, National Aids Control Organisation (NACO) has worked hard to ensure the safety of the blood and reduce transfusion-transmitted infections (TTIs) due to Hepatitis B and C, HIV, etc.

1. Thalassemia; Mayo Clinic

2. Thalassemia is a man-made disaster: Dr. J.S. Arora; ET HealthWorld, June 10, 2019

3. Treatment of Thalassemias; Hematology-Oncology Associates of CNY

4. 'India has largest number of kids with Thalassemia Major'; Tribune India, August 18, 2020



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India has the highest number of Thalassemia patients globally, with more than 10,000 children born with this disability every year.<sup>5</sup> Thalassemia major and the severe form of Thalassemia Intermedia (TI) account for the significant burden of this disease in the country.<sup>6</sup> ~50 per cent of people with this disability do not survive beyond 20 years due to poverty and inability to afford treatment.<sup>7</sup> Thalassemia has been included in the Rights of Persons with Disabilities Act (RPWD), 2016. The Act offers various benefits to people who have this disability, such as reasonable accommodation,

reservation in higher education, and non-discrimination in the workplace.<sup>8</sup>

In 2020, the Indian Red Cross Society established a Thalassemia Screening and Counselling Centre at its headquarters in New Delhi to offer screening programmes, information and raise awareness to assist in the prevention of children affected with hemoglobinopathies (Thalassemia and sickle cell disease).<sup>9</sup>



According to Dr Sunil Gupta, Director - National Blood Transfusion Council & Additional DGHS, NACO, there are 3,300 blood centres in the country; NACO supports 1,100. India has witnessed a transition from professional blood donation to voluntary blood donation. NACO aims to reach the target of 100 per cent voluntary blood donation, from the current level of 70 per cent. Gujarat, Maharashtra, Karnataka, Kerala, and Tamil Nadu have reported more than 90 per cent blood donation. But there are few states where voluntary blood donation is around 30-35 per cent due to limiting factors such as prevailing culture and mindset of the population. Therefore, these states have been guided to replicate the model adopted by well-performing states to enhance the share of voluntary blood donation.

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5. World Thalassemia Day 2021: Thalassemia, an inherited blood disorder, in Children; Financial Express, May 8, 2021
6. Dr. Harsh Vardhan inaugurates the Thalassemia Screening and Counselling Centre at Indian Red Cross; Press Information Bureau, August 18, 2020
7. World Thalassaemia Day: Symptoms, Prevention & Other Facts To Know About The Condition; The Economic Times, May 8, 2020
8. Blood disorders included in The Rights of Persons with Disabilities (RPWD) Act, 2016 Explained; DEOC, October 22, 2018
9. Thalassemia Screening and Counselling Centre; Indian Red Cross Society, August 18, 2020



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The COVID-19 pandemic introduced various challenges for the patients who have this disability. However, it also offered an opportunity for medical professionals to think outside the box and look for productive pathways to overcome these challenges.

## Challenges faced amid the pandemic<sup>10</sup>

**Shortage of blood in blood banks**

**Decline in voluntary blood donation**

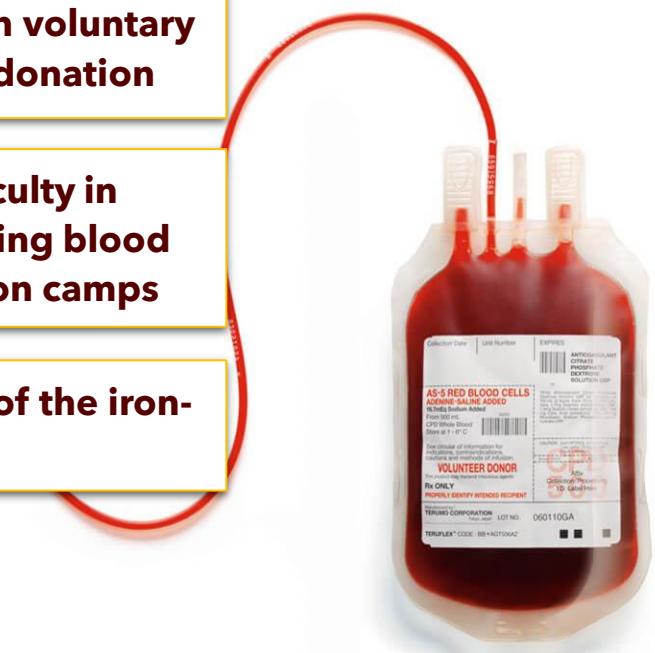
**Unavailability of transportation and transfusion facilities**

**Difficulty in organizing blood donation camps**

**Hampered production and supply of the iron-chelating medicines**

Globally, the situation was very similar, as travel restrictions led countries to also witness a decline in voluntary blood donation amid the pandemic.

In collaboration with the community (scientific and patient), the government tried to overcome these issues. The initiatives taken during the pandemic included introducing separate entry and exit gates for voluntary donors and issuing certificates to the donors so that they could visit the centres, especially when



travel restrictions were in place. Measures also included reaching out to donors through WhatsApp to inform them about these safety precautions, launch mobile blood collection vans, and mobilise voluntary donations through social media.

10. World Thalassemia Day 2021: COVID-19 and the Importance of Donating Blood; News 18, May 8, 2021



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The Ministry of Health also introduced guidelines for the organization of blood donation camps. Similarly, guidelines were issued by National Blood Transfusion Council (NBTC) regarding blood donation amid the pandemic.<sup>11</sup> Multiple cities organized the camps and followed all the safety protocols. Several private players such as Khoon, Rashtriya Swayamsevak Sangh (RSS), the Indian Red Cross Society, and Thalassemics Patients Advocacy Group (TPAG) all came together to assist thalassemia patients during these testing times.<sup>12</sup> Agencies made use of blood

collection vehicles to make it easier for the donors to donate blood during this time. The State Blood Transfusion Councils (SBTC) in states also encouraged private bodies and non-profit organizations (NPOs) to offer their suggestions and help the state in maintaining sufficient blood collection.

A notable step taken by the state of Karnataka was the introduction of a blood collection vehicle, which SBTC ran in alliance with the National Health Mission (NHM).

11. Blood Donations Drop by 75% Due to COVID-19, Here's How to Help; The Quint, April 23, 2020

12. As Some Blood Banks Run Dry Due To COVID-19 Lockdown, Thalassemia Patients Fear For Lives; Outlook, April 10, 2020



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Experts at the session also deliberated the requirement for a consolidated blood regulation, separate from the Drugs and Cosmetics Act, as NBTC does not have adequate power. The guidelines that NBTC and SBTC issue are voluntary and have no legal application. Currently, the blood services in the country are being managed by three distinct bodies:

- Drug Controller General of India manages the legislative part
- NBTC introduces standards, guidelines and advisory
- National Health Mission offers support to blood centres and allots budget

The Government has constituted a committee to review this issue and form a single organization solely responsible for blood-related services.

Experts at the webinar also discussed the Disability Law of 2016 and its benefits to thalassemia patients during the pandemic. They highlighted the urgent need to enhance awareness about thalassemia, problems faced by people with this disability, and the Act's benefits. Panelists agreed that a single interface to link people, all the agencies, and the Government would help reduce the current lacuna in the segment.

## ASSOCHAM recommendations

- Generate awareness among masses regarding **blood donation** to remove regional disparity in blood collection
- Develop stringent rules to drive **implementation of the guidelines** set by the NBTC for the adoption and implementation of safe blood practices
- Promotion of **carrier screening**, pre-marital and pre-conception screening, and genetic counseling
- Educate people** about the symptoms, how to manage the disease, and treatments available
- Enhance R&D efforts to **identify new treatments** to decrease the frequency of blood transfusion
- Improve **access to Nucleic Acid Testing** (NAT) - such blood reduces the risk of contracting transfusion-transmitted infections
- Reduce the **cost of stem cell and bone marrow treatment** for these patients
- Improve availability of **generic medicines** at affordable rates

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11. India Covid: Government says new variant linked to surge; BBC News, May 6, 2021
12. Virus strain in India has mutations that increase transmission, says top WHO scientist; Scroll.in, May 10, 2021
13. To Fight the Deadly Second Wave, a Lockdown Is the Only Available Strategy; The Wire, April 25, 2021
14. Resurgence of COVID-19 in India: A Tale of Six Unlearnt Lessons; The Wire, April 8, 2021



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## Panel experts

- Mr. Anil Rajput, Chairperson, AFCSR
- Ms. Anubha Taneja Mukherjee, Member Secretary, Thalassemics Patients Advocacy Group (TPAG)
- Dr. Sunil Gupta, Director - National Blood Transfusion Council & Additional DGHS, NACO
- Mr. Deepak Chopra, President, Thalassemics India
- Dr. Pawan Kumar Singh, Head of Oncology, Organ Transplant, Hematology Hematopoietic Stem Cell Transplant Department, Artemis Hospital
- Dr. Amita Mahajan, Senior Consultant, Pediatric Hematology and Oncology Indraprastha Apollo Hospitals
- Mr. Chetan Manchegowda, Founder, Khoon
- George Constantinou, Board Member, Thalassaemia International Federation
- Mr. Rajesh Mittal, Founder and Chairman Alamat Capital Advisors; and President, Rotary District 3011

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