



# FEDERATION of Indian Thalassemics NATIONAL THALASSEMIA BULLETIN



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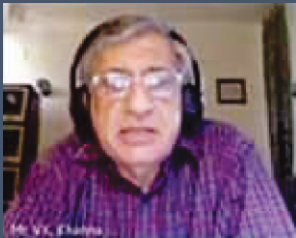
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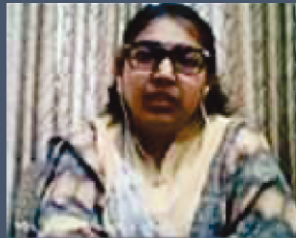
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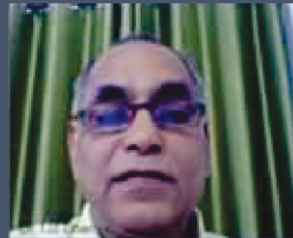
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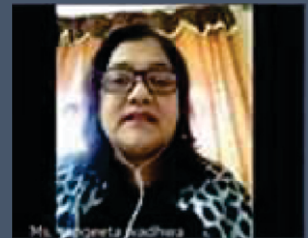
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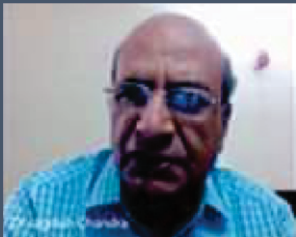
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A Glimpse of Webinar Discussion



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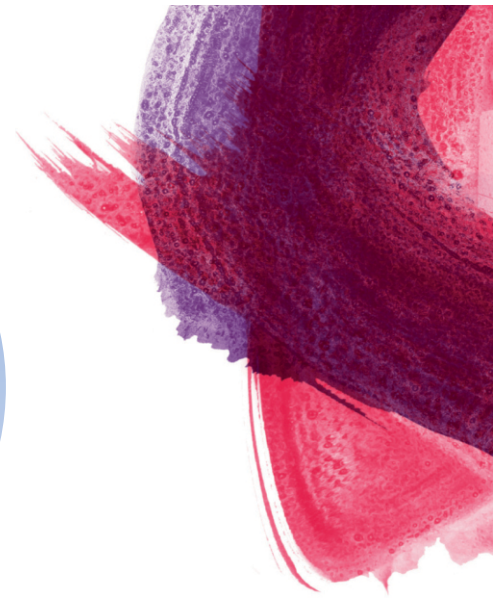
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<sup>1-2</sup> Data from Center 1 (Germany, 2016); residual WBC counting by flow cytometer.





## Thalassemics Challenges During Corona Pandemic

Corona (COVID-19) infection started from Wuhan China in December-19 & since then it has spread all over the World like a wild fire. World Health Organization (WHO) has declared as pandemic. Till 25th June 92,96,202 Individuals all over the World have been infected & of these 4,79,133 have died. The worst affected countries are USA, Brazil, Russia, India, UK, Spain, Italy, Peru, Iran & Germany in that order. In India there were only 30 cases as on 5th March 20 but on June 25th 4,73,105 have been infected & of which 14,894 have died.

Worst affected states include Maharashtra, Tamil Nadu, Delhi, and Gujarat. This indicates that Corona infection is spreading very fast & has higher mortality as compared with other viral infections. All over the World it is now believed that Corona virus is going to be with us like other viral infections. Therefore the scientists all over the World are working to develop vaccine & newer effective drugs against Corona virus.

Government of India had initiated complete lockdown on 24th March 20 till 1st June to arrest its spread & to develop necessary medical infrastructure, equipment, PPE, masks etc to fight with Corona infection & to ensure that most of people who suffer should have speedy recovery. This lock down certainly slowed down the spread of infection as compared with other countries where lockdown was either initiated late or it was partial.

Challenges of our Thalassemics had increased multifold during the lockdown & are likely to stay till we are able to control the infection & normalcy returns in the health care services. However some of their difficulties will ease with the unlocking & efforts by the Government & Thalassemia Societies.

In this newsletter Professor Chandra has given very good news with convincing data that Corona virus is not transmitted through blood & blood products. Thalassemics children if they get Corona infection recover quickly as they are more health conscious & are brave warriors. However Thalassemics children with complications such as with obesity, diabetes, heart or liver problems, who have undergone splenectomy are at higher risk of acquiring Corona infection & should take all precautions which have been well described by him. It is my sincere request to all members of Thalassemics families to follow those guidelines to prevent the entry of Corona in your houses. The challenges faced by our Thalassemics are described in brief along with necessary measures to overcome them to ensure that you all are able to maintain the desired hemoglobin & serum ferritin levels.

### BLOOD AVAILABILITY:

In the initial phase of lock down blood was available however as the lockdown progressed the blood availability became scarce because of multiple reasons such as 1. Blood donation camps could not be held 2. All colleges, factories, offices, corporates etc. were closed. 3. Blood donations in hospitals were less as routine admissions & surgery were stopped, 4. Donors were not willing to come to hospitals because of lockdown & as such they were scared of Covid infection, 5 Social

workers also couldn't work during lockdown. Some of the blood banks e.g Rotary blood bank almost closed down its services during the lockdown period. & Blood collected in some hospitals & blood banks is given in table 1. It is obvious that availability of blood was much less from lockdown onwards & it is likely to continue till the normalcy returns.

**TRANSFUSION THERAPY:** Getting blood transfusion which is life line for Thalassemics became a challenge from the lockdown period onwards for several reasons such as 1. Children could not come to day care centres as public transport was not available 2. Need of pass to travel from their house to hospitals 3. Children from containment zone or red areas had additional challenges 4. The scare of Corona infection, 5 Non-availability of blood or bed in day care centers as some places beds were reduced to keep the appropriate social distancing. Their challenges increased further as some hospitals were declared as Covid hospitals such as LNJP, GTBH, Hindu Rao in Delhi, SGPGI in Lucknow etc without making appropriate alternative arrangements for Thalassemics. Other hospitals were not willing to take these children because of non availability of beds or blood. However subsequently with intervention of Govt & Thalassemic Societies alternative arrangements have been made. During this period many of these children got their transfusion in some local nursing homes or nearby hospitals without the supervision of experts. Number of Thalassemics in a major day care centre in Delhi where nearly 350 children are registered only 50 to 60 percent of blood was transfused at that centre because of multiple reasons. Similar was my data at Batra Hospital in Delhi & Fortis Escorts Hospital at Faridabad where nearly 70 percent of children could get the transfusions. The woes of these children increased further as some of the Hospitals started doing Covid test which added to their financial burden. They were already under financial burden as they had to make their travel arrangements for transportation as public transport was not available from lockdown period onwards & even at present the public transport facilities are limited. It is suggested that during these challenging times Thalassemics should arrange their donors & even parents can donate blood. Many parents are under false impression that they can't donate blood as they are Thalassemia minor which is totally wrong. All of you requested to motivate your relatives, friends, colleagues etc to donate the blood to ensure that your child continues to get blood regularly during this pandemic.

### CHELATION THERAPY:

Chelation therapy had bigger set back as all of you were getting these drugs from your day care centres either free or with subsidies every month. You could not get these drugs as you could not attend the day care centres for transfusion for various reasons. You could not buy these drugs as they are not available in any pharmacy. Thalassemics societies couldn't mail the drugs as there was no courier services. My fear is that in many of you serum ferritin would have risen to quite high levels which can have adverse affect & may cause complications secondary to iron overload. It is suggested that you should procure your chelation

drugs from your Thalassemia society or from your day care centres. It is advised that you should keep some stock at least during this pandemic period. My sincere suggestion is that you should take all efforts to maintain your serum ferritin around 1000 ng/ml. You should consult your doctors regularly. You may consult me or your Thalassemic society for advice if necessary.

### MONITORING OF THALASSEMIA :

You all know very well the importance of regular monitoring. No one can assess the serum ferritin, liver & renal, cardiac functions just by clinical examination. These tests are undertaken regularly to detect any abnormalities early to take appropriate measures to prevent irreversible damage to any organs. Many of you may not be able to get all the facilities either at your own day care centres or at alternative places during this pandemic for various reasons beyond the control of your doctors or societies. It is our sincere suggestion that all of you should ensure that regular monitoring is being undertaken as before. In addition you should get the monitoring of tests for any complications if you have such as diabetes, hypothyroidism, growth retardation, cardiac or liver complications etc.

### BONE MARROW TRANSPLANTATION (BMT) :

BMT offers complete cure if you have sibling matched donor. Some of you had planned to undergo BMT & it has been postponed because of the Corona pandemic which may continue throughout this year. It is an elective procedure for Thalassemia. All experts are of the opinion that BMT is very dangerous during this pandemic as your immune system becomes very weak after the BMT & it takes minimum of one year to recover. Our fear is that if any one develops Corona infection after BMT then the infection will be very severe & it may become difficult to save the precious life. Therefore it is suggested that none of you should insist for BMT. We know well that some of you who are at low risk today may enter the high risk zone because of your age, & risk factors such as liver size, serum ferritin levels, cardiac or other endocrine status. Among various above factors except age all other factors are under your control by following all principles of Thalassemia management, monitoring of various tests & preventing the development of any complications. Parents can use this time to select the BMT centre make necessary financial & other arrangements. They should remain in touch with their centre & follow their advice to ensure that your child becomes more suitable for BMT for better results.

### THALASSEMICS SOCIETIES :

National Thalassemia Welfare Society & all other societies in our country have been highly concerned about your welfare & have been doing their best in spite of various odds & lockdown. Measures they have taken include 1. Increasing transfusion services by interacting with various nursing homes / smaller hospitals

2. Arranging blood through various blood banks or directing the donors to appropriate places.

3. NTWS got curfew pass for its vehicle to provide transport for Thalassemics & donors

4. Providing chelating drugs

5. Interacted with Central & state Governments to provide alternative arrangements in other hospitals if the hospitals having day care centres were declared as Covid hospitals.

6. NTWS provided tele consultancy to all Thalassemia children & arranged Webinar for doctors along with IAP Delhi & for Thalassemia children to provide update on Corona infection & its impact on Thalassemia management.

I convey my sincere wishes for your best health during this pandemic. Kindly take all precautions to stay safe & take good care of your health to prevent any complications of disease. God bless you & your family members with good health & prosperity.

### Dr. V. P. Choudhry

Sr. Consultant Hematology

1. Batra Medical Research Center & Hospital Delhi
2. Fortis Escorts Hospital Faridabad

### Formerly

1. Prof & Head Department of Hematology AIIMS New Delhi
2. Director IGICH Kabul Afghanistan
3. President of Delhi Society of Hematology & Indian Society of Hematology & Blood Transfusion

### Breaking News

#### Genotype SC test developed

A simple dipstick test which can detect presence of sickle cell even in newborns in 10 minutes has been developed in the World which is being validated by World Health Organisation. This test reads out Haemoglobin(Hb) types such as HbAA, HbAS, HbSS, HbSC, HbAC, HbCC. It is based on highly specific monoclonal antibodies to above Haemoglobins. Thus this test can be done even newborns when HbF levels are high. This test has specificity & sensitivity of over 99 percent. This test will be of great help in our country where sickle cell anemia is very common along with other Haemoglobinopathies.



Dr. Jagdish Chandra, MD, FIAP  
Director Professor of Pediatrics  
LPMC and Associated Kalawati Saran Children's Hospital, New Delhi

For the last over 6 months, world is going through very difficult times due to Corona virus infection (also called as Covid-19). As on 25.06.2020 Covid-19 has infected over 92,96,202 lacs individuals in the world of which over 4,79,133 lacs have unfortunately died. In India, current infection statistics is over 4,73,105 with over 14,894 deaths. Central and state governments have taken several steps for control of spread of this infection. Lockdown with stoppage of all kinds of travel, closure of markets etc is one important step undertaken by the government.

Patients with thalassemia are concerned about chances of their getting infected during hospital visits or otherwise. They have a fear that they may have more severe disease. Following description of Covid-19 in thalassemics will allay some of the anxiety of these patients:

## Covid-19 infection in TDT/NTDT:

As the information stand today, it appears that patients with thalassemia are not at increased risk of Covid-19 infection. A report from Italy has highlighted that the patients of thalassemia syndromes are likely to be more hygiene conscious, they have not got infection frequently. Italy observed Covid-19 in 11 of TDT/NTDT patients. Three of them were asymptomatic. Only six required hospitalization and fortunately their course was only moderate to severe with none of them requiring ventilation. All patients recovered in 2-4 weeks' time. No corona Infections in TDT/NTDT in India are reported till now. It is worthwhile mentioning that hypertension, diabetes, chronic lung disease, pulmonary hypertension, obesity are risk factors for severe disease. Some of the thalassemics may be having these risk factors and should observe extra care.

It may also be noted that till now there is no evidence that corona virus is transmitted by blood/ blood product transfusion.

## Effects of Covid-19 on Thalassemia Care:

Covid-19 and resultant problems arising out of lockdown have affected the care of patients of thalassemia in more than one ways. Not only the availability of blood products has become limited, travel to transfusion centre has also been made difficult. Following are the effects of Covid-19 on thalassemia care and the steps taken to tackle the problems arising out of Covid-19 infection and lockdown:

### 1. Transfusion related problems:

Patients with transfusion dependent thalassemia (TDT) are not able to get their due transfusions. There are several contributing factors to this:

i) Some hospitals have been converted to special Covid hospitals, with the result patients registered in these hospitals are facing problems. Other hospitals which are already overcrowded are not able to accommodate additional patients.

ii) Patients coming from different 'zones'- Covid related categorization- Green, Orange and Red need to be kept segregated during hospital stay for transfusion.

iii) Scarcity of blood products: blood donations have tremendously diminished over last 2-3 months. This has resulted from a) fear of donors to visit the hospitals for donation, b) not able to organize the blood donation camps because of 'social distancing' and travel restrictions etc.

iv) Patients are not coming to their transfusion centres because of fear of contracting the infection or simply because of travel problems due to lockdown.

v) Hospitals are not able to procure leucodepletion filters due to lockdown

vi) Lack of preparedness of hospitals due to limited supply of protective gears.

### 2. Inadequate Chelation:

Chelation is likely to be affected though less severely than transfusion. Patients are finishing their supply of drugs and are not able to reach the hospital or not coming to hospitals to replenish the drugs. On the other hand lockdown has interrupted the supply chain of drug procurement of hospitals.

### Measures taken to tackle the situation :

Fortunately the problems arising out of lockdown are taken note off and several steps have been taken to address the problems. These include:

- Special drive for blood donations by putting request in different WhatsApp groups.
- Donor passes are issued by e-mail or WhatsApp to facilitate the travel to and from the blood banks
- Blood collection areas in the blood banks are safe areas and this has been displayed in hospitals to allay the fear of prospective donors
- NGOs have been roped in to motivate the individual donors
- Patients have been advised to bring their donors.
- Parents are advised to donate blood and be prepared to donate in future as well if the lockdown or similar restrictions persist
- Rationing of blood is resorted to as the available units are less hence more needy are being given the blood.
- As the restrictions are easing out, blood donation camps are being organized.



- i. Patients from different zones are being transfused in different wards (other than designated transfusion centres) to minimize hospital acquired Covid-19 infection.

These steps hopefully will effectively address the transfusion needs of the patients.

### Prevention of Corona Infection :

For prevention of corona infection, general guidelines circulated by Govt of India from time to time should be strictly followed. These include:

- a. Stay home as far as possible
- b. Wearing mask when going out of home
- c. Avoid going to crowded places completely
- d. Wash your hands and face with soap after coming back from outside
- e. Observe social distancing while outside home (two meter distance between individuals)
- f. Frequent washing of hands with soap for 20 seconds
- g. Use of appropriate sanitizers
- h. Use of respiratory etiquettes such as covering the nose with tissue paper or a cloth while sneezing or coughing.

- i. Use tissue paper to clean the nose
- j. Do not touch the mouth, eyes and nose unnecessarily
- k. Use home remedies for improving immunity such as drinking ginger and Tulsi tea, use of haldi (turmeric) and homemade concoction (kaadaa)

Those thalassemics who are working, should “work from home” as far as possible. Aogya setu is an app which can be downloaded. This helps by telling our health status and whether there are any Covid-19 patients in the vicinity. Patients with thalassemia should not be unnecessarily worried for missing one or two transfusions or chelators over a few days. A telephonic communication with centres will be helpful.

### Conclusions :

Going by the current status of spread of Covid-19, it does not appear that the things will get back to normal soon. In fact we might have to face a 'new normal' including travel restrictions, social distancing etc.

**Some of the problems of patients with thalassemia would not have occurred if long distance travel for transfusions was not required. That could have been possible only if a large number of thalassemia care centres were present in each state. The problem of Covid-19 should be used as an opportunity for establishing more and more centres for care of thalassemia and hemoglobinopathies.**

## कोरोना महामारी और लॉकडाउन के दौरान थैलेसीमिया देखभाल

### डॉ जगदीश चंद्र, एमडी, एफआईएए

बाल रोग के निदेशक प्रोफेसर

एलएचएमसी और एसोसिएटेड कलावती सरन चिल्ड्रेन्स हॉस्पिटल, नई दिल्ली

पिछले 6 महीनों से कोरोना वायरस के संक्रमण (जिसे कोविड -19 भी कहा जाता है) के कारण दुनिया बहुत मुश्किल दौर से गुजर रही है। 25.06.2020 तक कोविड -19 ने दुनिया के 92,96,202 लाख से अधिक व्यक्तियों को संक्रमित किया है, जिसमें 4,79,133 लाख से अधिक दुर्भाग्य से मारे गए हैं। भारत में, 14,894 से अधिक मौतों के साथ वर्तमान संक्रमण के आंकड़े 4,79,105 से अधिक हैं। केंद्र और राज्य सरकारों ने इस संक्रमण के प्रसार पर नियंत्रण के लिए कई कदम उठाए हैं। सभी प्रकार की यात्रा को रोकना, बाजारों को बंद करना आदि महत्वपूर्ण कदम हैं

थैलेसीमिया के मरीजों को अस्पताल की यात्राओं के दौरान या अन्यथा संक्रमित होने की संभावना है। उन्हें अंदेशा है कि उन्हें और अधिक गंभीर बीमारी हो सकती है। थैलेसीमिक्स में कोविड -19 के वर्णन के बाद इन रोगियों की चिंता दूर हो जाएगी:

### TDT / NTDT में कोविड -19 संक्रमण:

आज तक की जानकारी से ऐसा प्रतीत होता है कि थैलेसीमिया के रोगियों को कोविड -19 संक्रमण का अतिरिक्त खतरा नहीं है। इटली की एक रिपोर्ट में

बताया गया है कि थैलेसीमिया सिंड्रोम के रोगियों में स्वच्छता के प्रति अधिक सचेत होने की संभावना है, उन्हें अक्सर संक्रमण नहीं होता है। इटली ने TDT / NTDT के 11 रोगियों में कोविड -19 का अवलोकन किया। उनमें से तीन लक्षण रहित थे। केवल छह को अस्पताल में भर्ती करने की आवश्यकता थी और सौभाग्य से उनका स्तर केवल मध्यम से गंभीर था और उन्हें वेंटिलेशन की आवश्यकता नहीं थी। 2-4 सप्ताह के समय में सभी रोगी ठीक हो गए। भारत में TDT / NTDT में कोई कोरोना इन्फेक्शन अब तक नहीं बताया गया है। यह उल्लेखनीय है कि उच्च रक्तचाप, मधुमेह, पुरानी फेफड़ों की बीमारी, फुफ्फुसीय उच्च रक्तचाप, मोटापा, गंभीर बीमारी के जोखिम कारक हैं। कुछ थैलेसीमिक्स में ये जोखिम कारक हो सकते हैं और उन्हें अतिरिक्त देखभाल का अनुसरण करना चाहिए।

यह देखने में आया है कि अब तक कोई सबूत नहीं है कि कोरोना वायरस रक्त / रक्त उत्पाद आधान द्वारा फैलता है।

### थैलेसीमिया देखभाल पर कोविड -19 के प्रभाव:

कोविड -19 और लॉकडाउन से उत्पन्न होने वाली परिणामी समस्याओं ने एक से अधिक तरीकों से थैलेसीमिया के रोगियों की देखभाल को प्रभावित किया है। न केवल रक्त उत्पादों की उपलब्धता सीमित हो गई है, बल्कि ट्रांसफ्यूजन सेंटर की यात्रा भी मुश्किल हो गई है। थैलेसीमिया देखभाल पर कोविड -19 के प्रभाव



और कोविड-19 संक्रमण और लॉकडाउन से उत्पन्न समस्याओं से निपटने के लिए उठाए गए कदम निम्नलिखित हैं:

### 1. आधान संबंधी समस्याएं:

आधान पर निर्भर थेलेसीमिया (टीडीटी) के मरीजों को उनके निर्धारित आधान नहीं मिल पा रहे हैं। इसके लिए कई योगदान कारक हैं:

i) कुछ अस्पतालों को विशेष कोविड अस्पतालों में बदल दिया गया है, जिसके परिणामस्वरूप इन अस्पतालों में पंजीकृत रोगियों को समस्याओं का सामना करना पड़ रहा है। अन्य अस्पताल जो पहले से ही भीड़भाड़ वाले हैं, अतिरिक्त रोगियों को समायोजित करने में सक्षम नहीं हैं।

ii) विभिन्न क्षेत्रों से आने वाले मरीजों को कोविड संबंधित वर्गीकरण- ग्रीन, ऑरेंज और रेड के आधार पर आधान के लिए अस्पताल में रहने के दौरान अलग रखा जाना चाहिए।

iii) रक्त उत्पादों की कमी: पिछले 2-3 महीनों में रक्त दान में भारी कमी आई है। क) इससे दानदाताओं को दान के लिए अस्पतालों में जाने का डर पैदा हो गया है, ख) आवश्यक दूरी और यात्रा प्रतिबंध आदि के कारण रक्तदान शिविर आयोजित करने में असमर्थता है।

iv) संक्रमित हो जाने के डर से या केवल लॉकडाउन के दौरान यात्रा की समस्याओं के कारण रोगी अपने आधान केंद्रों में नहीं आ रहे हैं।

v) अस्पताल लॉकडाउन के कारण लेयुकोडीप्लिटिंग फिल्टर की खरीद करने में सक्षम नहीं हैं

vi) सुरक्षात्मक उपकरणों की सीमित आपूर्ति के कारण अस्पतालों की तैयारियों में कमी।

### 2. अपर्याप्त चिलेशन:

रक्ताधान की तुलना में चिलेशन द्वारा गंभीर रूप से प्रभावित होने की संभावना कम है। मरीज अपनी दवाओं की आपूर्ति खत्म कर रहे हैं और दवाओं की भरपाई करने के लिए अस्पताल नहीं पहुंच रहे हैं या नहीं पहुंच पा रहे हैं। दूसरी ओर लॉकडाउन ने अस्पतालों की दवा खरीद की आपूर्ति श्रृंखला को भी बाधित किया है।

### स्थिति से निपटने के लिए किए गए उपाय:

सौभाग्य से लॉकडाउन से होने वाली समस्याओं पर ध्यान दिया जा रहा है और समस्याओं को दूर करने के लिए कई कदम उठाए गए हैं। इसमें शामिल है:

क) विभिन्न व्हाट्सएप समूहों में अनुरोध डालकर रक्तदान के लिए विशेष अभियान।

ख) रक्त बैंकों द्वारा यात्रा की सुविधा के लिए ई-मेल या व्हाट्सएप द्वारा डोनर पास जारी किए जाते हैं

ग) रक्त बैंकों में रक्त संग्रह क्षेत्र सुरक्षित क्षेत्र हैं और यह अस्पतालों में संभावित

दाताओं के डर को कम करने के लिए प्रदर्शित किया गया है

घ) स्वयं सेवी संस्थाओं को व्यक्तिगत दाताओं को प्रेरित करने के लिए जोड़ा गया है

ण) मरीजों को अपने लिए रक्त दाताओं को लाने की सलाह दी गई है।

च) माता-पिता को सलाह दी जाती है कि वे रक्त दान करें और आगे भी तैयार रहें अगर लॉकडाउन या इसी तरह के प्रतिबंध जारी रहें

छ) रक्त की राशनिंग का सहारा लिया जाता है क्योंकि उपलब्ध इकाइयाँ कम होती हैं इसलिए अधिक जरूरतमंदों को रक्त दिया जा रहा है।

ज) जैसे-जैसे प्रतिबंधों में ढील हो रही है, रक्तदान शिविर आयोजित किए जा रहे हैं।

झ) अस्पताल से कोविड -19 संक्रमण को कम करने के लिए विभिन्न क्षेत्रों के मरीजों को अलग-अलग वार्डों (नामित आधान केंद्रों के अलावा) में स्थानांतरित किया जा रहा है।

आशा है ये कदम प्रभावी रूप से रोगियों के आधान की जरूरतों को पूरा करेंगे।

### कोरोना संक्रमण की रोकथाम:

कोरोना संक्रमण की रोकथाम के लिए, भारत सरकार द्वारा समय-समय पर प्रचारित सामान्य दिशानिर्देशों का कड़ाई से पालन किया जाना चाहिए। इसमें शामिल है:

क) जहां तक हो सके घर में रहें

ख) घर से बाहर जाते समय मास्क पहने

ग) भीड़-भाड़ वाली जगहों पर जाने से पूरी तरह बचें

घ) बाहर से वापस आने के बाद अपने हाथों और चेहरे को साबुन से धोएं

ण) घर से बाहर रहने के दौरान सामाजिक दूरी का पालन करें (व्यक्तियों के बीच दो मीटर की दूरी)

च) 20 सेकंड के लिए साबुन से हाथों को बार-बार धोना

छ) उपयुक्त सैनिटाइज़र का उपयोग

ज) छींकते या खांसते समय श्वसन शिष्टाचार का उपयोग जैसे टिशू पेपर या कपड़े से नाक को ढंकना

झ) नाक साफ करते समय को टिशू पेपर का उपयोग करें

न) मुंह, आंख और नाक को अनावश्यक रूप से न छुएं

त) प्रतिरक्षा में सुधार के लिए घरेलू उपचार का उपयोग करें जैसे कि अदरक और तुलसी की चाय पीना, हल्दी (हल्दी) का उपयोग करना और घर का बना काढ़ा

जो थेलेसीमिक्स काम कर रहे हैं, उन्हें "घर से काम" करना चाहिए। आरोग्य सेतु एक ऐप है जिसे डाउनलोड किया जा सकता है। यह हमारे स्वास्थ्य की

स्थिति और यह बताता है कि आसपास के क्षेत्र में कोई कोविड -19 मरीज हैं या नहीं। थैलेसीमिया के रोगियों को एक या दो आधान या कुछ दिनों के लिए चिलेशन अवरुद्ध होने पर अनावश्यक रूप से चिंतित नहीं होना चाहिए। केंद्रों के साथ एक टेलीफोनिक संचार मददगार होगा।

#### निष्कर्ष:

कोविड -19 के प्रसार की वर्तमान स्थिति के अनुसार, ऐसा नहीं लगता है कि हालात जल्द ही सामान्य हो जायेंगे। वास्तव में हमें यात्रा प्रतिबंधों, सामाजिक दूरी आदि सहित एक नए सामान्य 'का सामना करना पड़ सकता है

अगर रक्ताधान के लिए लंबी दूरी की यात्रा की आवश्यकता नहीं होती, तो थैलेसीमिया के रोगियों की कुछ समस्याएं कम हो सकती थीं। यह तभी संभव हो सकता था जब प्रत्येक राज्य में बड़ी संख्या में थैलेसीमिया देखभाल केंद्र मौजूद होते। कोविड -19 की समस्या का उपयोग थैलेसीमिया और हीमोग्लोबिनोपैथी की देखभाल के लिए अधिक से अधिक केंद्रों की स्थापना के अवसर के रूप में किया जाना चाहिए।

## WEBINAR : 26th International Thalassemia Day 2020

8th May is observed as International Thalassemia Day (ITD) world over. This time it was 26th ITD. We had planned a big congregation of Thalassemics, Govt. officials and doctors involved in management of thalassemia at constitution club but due to lockdown because of Covid 19 pandemic we converted it into a webinar on Saturday 9th May 2020 from 3pm to 5pm. A galaxy of eminent panelist including Dr Androulla Elefetheriou, Executive Director Thalassaemia International Federation, Mr T D Dhariyal former State Commissioner for Persons with Disabilities, GNCT of Delhi & Dy Chief Commissioner for Persons with Disabilities, GoI, Dr VP Choudhry, former Prof. & Head Dept. of Hematology, AIIMS, Dr Jagdish Chandra, former Director Principal LHMC & Associated Hospitals, Mrs Vinita Srivastva, National Senior Consultant & Co-ordinator Blood cell –NHM, MoHFW Government of India, Dr VK Khanna Chairman, Dept. of Pediatrics, Institute of Child Health, SGRH, Dr Dinesh Bhurani Director Dept. of Hemato-oncology & BMT RGCI & Research Centre, Ms Sangeeta Wadhwa, Psychologist founder of YTA (YOUTH THALASSEMIA ALLIANCE), Mrs. Tanu Thakral, Former Patient counselor with NTWS. The webinar was in the format of question answer session. Dr JS Arora moderated the webinar. The language of the webinar was Hinglish (Hindi-English mixed).

In his opening remarks Dr Arora welcomed & congratulated the faculty and the audience on the occasion of 26th International Thalassemia Day. He explained the objectives and pressing situation of organizing this webinar.

Ms Sangeeta Wadhwa highlighted the specific problems faced by thalassemics during Covid pandemic was - how to get blood ? She said besides blood, transport and availability of medicines were other major issues.

She said she helped the fellow thalassemics by supporting them emotionally and arranging donors for them in Mumbai.

When asked Serum Ferritin or MRI T2\* which is better way to ascertain the iron overload and how frequently these tests should be done Dr VP Choudhry said serum ferritin is to measure circulating iron and MRIT2\* is to measure stored level, there is no liner correlation both are important Serum ferritin should be done every 3-4 months and

MRIT2\* should be done once a year

When asked whether Thalassemia minor can donate blood, he said anybody who is in the age group of 18- 65 years having hemoglobin level above 12 gm/dl can donate. Parents of thalassemia major are obligatory thalassemia minor they can also donate blood if their haemoglobin level is within normal limit. Rather I would stress they must donate during these hard time when there is acute shortage of blood.

Dr Androulla Elefetheriou while replying to a question If Covid 19 infection can be transmitted through blood transfusion? She said the risk of transmission is only theoretical. Patients treatment should remain uninterrupted, blood supply should be increased, keep your chelation on. She added the patients who are getting proper treatment are not in the danger, if they follow the national guidelines for social distancing, wearing mask and personal hygiene then they are not more prone to infection than general public

Dr Jagdish Chandra replying to a question informed that in India there is no thalassemic patient reported having covid 19. But in Italy 11 patients are reported as having Covid 19 and they were not showing more severe symptoms and they were treated with hydroxychloroquine. He added that there is no recommendation for using hydroxychloroquine as prophylaxis for public. It was advised by ICMR for hospital workers only.

While asked if covid 19 test is compulsory before transfusion Mrs Vinita Srivastava replied that it is not compulsory yet. But hospitals are asking for safety purpose of themselves as well as for patients. Some hospitals are using this strategy. She advised patients to use E Raktkosh portal for online request for donors. It shows current status of blood units/components available in blood banks all over India. Once you register for requirement of the blood you will get a message for availability of blood at a blood bank near to you within 1 - 2 days.

Regarding Coal India BMT project she said process has been held up because of Covid 19, after the pandemic is over we will do 200-300 transplantations.

When asked what tests should be done to monitor side effects of iron chelators and how frequently? Dr VK Khanna said CBC every one to two weeks and in every episode of fever patient should go for CBC, liver & kidney function tests once in two months, yearly hearing and eye check-up, also in every six month go for sitting and standing height check-up.

When asked what is the best age to undergo BMT and till what age one can think of transplantation if donor is available Dr Dinesh Bhurani said that in Covid era we should postpone all the transplantation but maintain chelation and haemoglobin till then. Patients age should be 2 years to 15 years some people can think up to 18 years but I prefer earlier is better

Mr TD Dhariyal former State Commissioner for Persons with Disabilities, GNCT of Delhi & Dy Chief Commissioner for Persons with Disabilities, Govt. of India while replying to questions on

disability said that Thalassemia will get the rights as all disabilities persons were getting, except job reservation. They cannot be discriminated in the method of employment or treatment. There are social security schemes like pension, land allotment, 5% reservation in educational admission and reasonable accommodation for which they are eligible. Replying to a question "How to get Disability certificate and UDID card," he said that go to any nearby District Govt hospital and give application; there are members who will do assessment, within one month you will get the certificate.

Login to [www.swavlambancard.gov.in](http://www.swavlambancard.gov.in) to get UDID card, if you have certificate you will get UDID card online in Delhi.

He said that district disaster management committee should have segregated data how many thalassemia patients are affected

## 26 वां अंतर्राष्ट्रीय थैलेसीमिया दिवस

8 मई को दुनिया भर में अंतर्राष्ट्रीय थैलेसीमिया दिवस (ITD) के रूप में मनाया जाता है। इस बार यह 26 वां आईटीडी था। हमने थैलेसीमिक्स, सरकारी अधिकारियों और डॉक्टरों, जो थैलेसीमिया के प्रबंधन में शामिल हैं के साथ संविधान क्लब में एक बड़ी सभा की योजना बनाई थी लेकिन कोविड-19 महामारी के लॉकडाउन के कारण हमने इसे शनिवार 9 मई 2020 को दोपहर 3 से शाम 5 बजे तक के एक वेबिनार में बदल दिया। प्रख्यात पैनेलिस्ट डॉ अन्डरूला, प्रबंध निदेशक थैलेसीमिया इंटरनेशनल फेडरेशन, श्री टी डी धारियाल विकलांगों के लिए पूर्व राज्य आयुक्त, दिल्ली सरकार और विकलांग व्यक्तियों के लिए उप मुख्य आयुक्त, केंद्र सरकार, डॉ वीपी चौधरी, पूर्व आचार्य एवं प्रमुख हेमटोलॉजी विभाग एम्स, डॉ जगदीश चंद्र, पूर्व निदेशक, प्रिंसिपल एलएचएमसी एवं एसोसिएटेड हॉस्पिटल्स, श्रीमती विनीता श्रीवास्तवा, नेशनल सीनियर कंसल्टेंट को-ऑर्डिनेटर ब्लड सेल-एनएचएम, स्वास्थ्य मंत्रालय, भारत सरकार, डॉ वीके खन्ना अध्यक्ष, बाल रोग संस्थान, गंगा राम अस्पताल, डॉ दिनेश भूरानी रुधिर कैंसर रोग विशेषज्ञ, निदेशक अस्थि मज्जा प्रत्यापण, विभाग राजीव गाँधी कैंसर संस्थान, सुश्री संगीता वाधवा, मनोवैज्ञानिक, संस्थापक, यूथ थैलेसीमिया अलायन्स एवं श्रीमती तनु ठकराल, पूर्व रोगी परामर्शदाता, NTWS ने सभा में भाग लिया। वेबिनार प्रश्न उत्तर सत्र के प्रारूप में था। डॉ जेएस अरोड़ा ने वेबिनार का संचालन किया। वेबिनार की भाषा हिंग्लिश (हिंदी-अंग्रेजी मिश्रित) थी।

डॉ अरोड़ा ने अपनी प्रारंभिक टिप्पणी में 26 वें अंतर्राष्ट्रीय थैलेसीमिया दिवस के अवसर पर विशेषज्ञों और दर्शकों का स्वागत किया और बधाई दी। उन्होंने इस वेबिनार के आयोजन के उद्देश्यों और बरबस स्थिति के बारे में बताया।

सुश्री संगीता वाधवा ने कोविड महामारी के दौरान थैलेसीमिक्स द्वारा सामना की जाने वाली विशिष्ट समस्याओं पर प्रकाश डाला है - रक्त कैसे प्राप्त करें, उन्हें अपनी प्रतिरक्षा प्रणाली में सुधार कैसे करना चाहिए। उन्होंने कहा कि रक्त के अलावा, परिवहन और दवाओं की उपलब्धता अन्य प्रमुख मुद्दे थे।

उन्होंने कहा कि उन्होंने साथी थैलेसीमिक्स को भावनात्मक रूप से समर्थन देकर और उनके लिए मुंबई में रक्तदाताओं की व्यवस्था करने में मदद की।

जब पूछा गया कि सीरम फेरिटिन या एमआरआई टी 2\* से लोहे के अधिभार का पता लगाने का बेहतर तरीका कोनसा है और इन परीक्षणों को कितनी बार किया जाना चाहिए तो डॉ वीपी चौधरी ने कहा कि सीरम फेरिटिन रक्त में संचारित लोहे को मापने के लिए है और एमआरआई टी 2\* संग्रहीत स्तर को मापने के लिए है इनका कोई सीधा संबंध नहीं है दोनों ही जाँच महत्वपूर्ण हैं। सीरम फेरिटिन हर 3-4 महीने में किया जाना चाहिए और MRIT2 \* साल में एक बार किया जाना चाहिए

यह पूछे जाने पर कि क्या थैलेसीमिया माइनर रक्तदान कर सकता है, उन्होंने कहा कि 18-65 वर्ष की आयु का कोई भी व्यक्ति जिसका हीमोग्लोबिन का स्तर 12 ग्राम/डीएल से ऊपर है रक्त दान कर सकता है। थैलेसीमिया मेजर के माता-पिता अनिवार्य रूप से थैलेसीमिया माइनर हैं वे रक्त दान कर सकते हैं यदि उनका हीमोग्लोबिन स्तर सामान्य सीमा के भीतर है। इसके बजाय मैं तो जोर दे कर कहता हूँ कि इस कठिन समय के दौरान रक्त कोष में रक्त की तीव्र कमी होने के कारण रक्त दान अवश्य करें।

डॉ अन्डरूला ने एक प्रश्न क्या कोविड-19 संक्रमण को रक्त आधान के माध्यम से प्रेषित किया जा सकता है? का उत्तर देते हुए कहा कि संचरण का जोखिम केवल सैद्धांतिक है। मरीजों का उपचार निर्बाध रहना चाहिए, रक्त की आपूर्ति बढ़नी चाहिए। अपनी चिलेशन पूरी करते रहो। उन्होंने आगे कहा कि जिन रोगियों को उचित उपचार मिल रहा है, वे खतरे में नहीं हैं, अगर वे मास्क पहनना, व्यक्तिगत स्वच्छता में और सामाजिक दूरी के लिए राष्ट्रीय दिशानिर्देशों का पालन करते हैं तो उन्हें संक्रमण का अधिक खतरा नहीं है।

डॉ। जगदीश चंद्र ने एक प्रश्न का उत्तर देते हुए बताया कि भारत में किसी भी



थैलेसीमिक रोगी में कोविड-19 होने की सूचना नहीं दी गई है। लेकिन इटली में 11 रोगियों में कोविड-19 होने की सूचना है और वे अधिक गंभीर लक्षण नहीं दिखा रहे हैं और उनका इलाज हाइड्रोक्सीक्लोरोक्विन से किया गया है। उन्होंने कहा कि जनता के लिए प्रोफिलैक्सिस के रूप में हाइड्रोक्सीक्लोरोक्विन का उपयोग करने के लिए कोई सिफारिश नहीं है। यह केवल अस्पताल कर्मियों के लिए आईसीएमआर द्वारा सलाह दी गई थी।

यह पूछे जाने पर कि क्या ट्रांसफ्यूजन से पहले कोविड-19 टेस्ट अनिवार्य है श्रीमती विनीता श्रीवास्तवा ने जवाब दिया कि यह अभी तक अनिवार्य नहीं है। लेकिन अस्पताल खुद के साथ-साथ मरीजों के लिए भी सुरक्षा के उद्देश्य से कर रहे हैं। कुछ अस्पताल इस रणनीति का उपयोग कर रहे हैं। उन्होंने मरीजों को रक्त दाताओं के लिए ऑनलाइन अनुरोध के लिए ई रक्त कोष पोर्टल का उपयोग करने की सलाह दी। यह पूरे भारत में ब्लड बैंकों में उपलब्ध रक्त इकाइयों/घटकों की वर्तमान स्थिति को दर्शाता है। एक बार जब आप रक्त की आवश्यकता के लिए पंजीकरण करते हैं, तो आपको 1 - 2 दिनों के भीतर आपके पास के एक ब्लड बैंक में रक्त की उपलब्धता के लिए संदेश मिलेगा।

कोल इंडिया बीएमटी परियोजना के बारे में उन्होंने कहा कि कोविड-19 की वजह से प्रक्रिया स्थगित है, महामारी खत्म होने के बाद हम 200-300 प्रत्यारोपण करेंगे।

यह पूछे जाने पर कि लोह निष्कासक दवाओं के दुष्प्रभावों की निगरानी के लिए क्या परीक्षण किए जाने चाहिए और कितनी बार? डॉ वीके खन्ना ने कहा कि हर एक से दो सप्ताह में और बुखार के हर एपिसोड में सीबीसी; दो महीने में एक बार सीबीसी, लिवर और किडनी के फंक्शन टेस्ट, हर छह महीने में बैठकर और खड़े होकर ऊंचाई जांच तथा सालाना सुनने और आंखों की जांच भी करनी चाहिए।

यह पूछे जाने पर कि बीएमटी करने के लिए सबसे सही उम्र क्या है और किस उम्र तक प्रत्यारोपण के बारे में सोच सकते हैं यदि दाता उपलब्ध हो तो, डॉ। दिनेश भूरानी ने कहा कि कोविड युग में हमें सभी प्रत्यारोपण स्थगित कर देने चाहिए लेकिन तब तक उचित हीमोग्लोबिन और चिलेशन बनाए रखना चाहिए। मरीजों की उम्र 2 साल से 15 साल तक होनी चाहिए कुछ लोग 18 साल तक सोच सकते हैं लेकिन मैं जितना जल्दी उतना बेहतर, पसंद करता हूँ

श्री टीडी धारियाल विकलांग व्यक्तियों के लिए पूर्व राज्य आयुक्त, दिल्ली सरकार और उप मुख्य आयुक्त, भारत सरकार ने विकलांगता पर सवालों का जवाब देते हुए कहा कि थैलेसीमिया को वैसे ही अधिकार मिलेंगे, जैसे अन्य सभी विकलांग मरीजों को मिल रहे थे, नौकरी में आरक्षण को छोड़कर।

उन्हें रोजगार या उपचार की विधि में भेदभाव नहीं किया जा सकता है। पेंशन, भूमि आवंटन, शैक्षिक प्रवेश में 5% आरक्षण और इसके अतिरिक्त उचित आवास जैसी सामाजिक सुरक्षा योजनाएं भी हैं। एक सवाल "विकलांगता प्रमाण पत्र और यूडीआईडी कार्ड कैसे प्राप्त करें" का जवाब देते हुए उन्होंने कहा कि किसी भी नजदीकी जिला सरकार अस्पताल में जाएं और आवेदन दें; वहां अधिकारीगण इसका मूल्यांकन करेंगे और एक महीने के भीतर आपको प्रमाणपत्र मिल जाएगा। UDID कार्ड प्राप्त करने के लिए [www.swavlambancard.gov.in](http://www.swavlambancard.gov.in) पर लॉग इन करें। यदि आपके पास प्रमाणपत्र है तो आपको दिल्ली में UDID कार्ड ऑनलाइन मिलेगा।

उन्होंने कहा कि जिला आपदा प्रबंधन समिति को कितने थैलेसीमिया रोगी प्रभावित हैं का लेखा जोखा अलग करना चाहिए

### Patna Blood Donation News During COVID-19

8 मई को विश्व थैलेसीमिया दिवस के मौके पर बिहार के सभी 36 सरकारी ब्लड बैंकों में लॉक डाउन के सभी दिशा निर्देशों का पालन करते हुए 46 संस्थाओं ने कोविड-19 जैसे मुश्किल घड़ी में थैलेसीमिया व अन्य पीड़ितों के लिए 266 यूनिट ब्लड डोनेशन का पुण्य कार्य किया है। इसके लिए विशेष तौर पर पटना के मां वैष्णो देवी सेवा समिति के मुकेश हिसारिया जी एवं उनकी समस्त टीम को बधाई एवं शुभकामनाएं, मानव सेवा ही माधव सेवा है और इसके लिए सतत प्रयास करते रहना चाहिए। सभी संस्थाओं को इस नेक कार्य के लिए अभिनंदन।







**North Eastern Thalassemia Society** in association with Indian Association of Pediatrics Assam Medical College, Dibrugarh organized a CME on thalassemia on 29th of June, 2019. Dr JS Arora & Dr VP Choudhry were the special invitees. Dr VP Choudhry spoke on "Treatment protocol and monitoring of "Thalassemic children & Curative options in Thalassemia".



Dr. JS Arora acquainted about "Chelation, Diet & Lifestyle adjustments in the Thalassemics life". He also delebrated on the Role of parents and societies in the upbringing of the thalassemic child. Dr Choudhry gave a lecture on anaemia to PG students & resident doctors. Concise book on Thalassemia "**Florilegium of Thalassemia**" written by Dr JS Arora was distributed among doctors and patients. Dr Choudhry and Dr Arora examined 53 patients and advised treatment.

**Thalassemia Welfare Society Jalandhar** organised a free medical check up and medicine donation camp on 30<sup>th</sup> June in Civil hospital, Jalandhar. Dr.J.S Arora was invited to examine the patients and prescribe the treatment.



Mr. Surjit Singh Khattar, The Managing Director of Help Thalassemics, distributed the Chelation drugs and other medicines to the needy patients. Members of social organizations like Agaaz Society, Sai Blood Sewa Society and pharma company Glaxo also attended the camp. They assured thalassemia patients that they will be



regularly donating blood to fulfil their requirement to maintain optimum level of haemoglobin. They also showed their commitment to raise awareness in public so that birth of new thalassemia major patients be prevented. Some members contributed financially to help the patients who aren't able to afford the treatment.



**ASTHA** a cross disability organization working with children with disabilities for more than 26 years, invited Dr JS Arora to create awareness on thalassemia to their staff at their head office on 11th july'19 at Basti Vikas Kendra, Kalkaji , New Delhi-110019. Another





Awareness Talk on blood disorder including thalassemia, was organized at Majdoor Kalyan Camp Okhla Phase-2 by ASTHA on 24<sup>th</sup> September. The primary aim of the talk was to sensitize the ASHA and Anganwadi workers about disability issues in children affected by blood disorders. Chetna a film on Thalassemia documented jointly by NTWS and Govt of Delhi was viewed to them. Mrs Monisha Gogoi and Aarti Yadav cleared their doubts. This program was sponsored by Tech Mahindra.



**Shree Guru Gobind Singh Tricentenary University, (SGT University),** invited Dr JS Arora and Dr VP Choudhry to a Thalassemia camp cum CME on 13th July 2019 at Budhera, district Gurugram Haryana. Dr VP Choudhry gave a talk on Management of Thalassemia & Dr JS Arora enlightened about Antenatal Diagnosis & Prevention of Thalassemia to PG students nurses.

YES Foundation an entity of Yes Bank under its CSR activity deputed 15 volunteers to NTWS for 7 weeks w.e.f. 10<sup>th</sup> June 2019. Their primary objectives were Content Writing, Social Media Campaigns, Filmmaking & Photography. They created animation stories on thalassemia awareness and blood donation, regularly posted posters on tips for thalassemia management, blood donation and prevention on LinkedIn, Twitter, Instagram and Facebook.



They visited hospitals and interacted with the patients. They also attended blood donation camps and motivated donors



**Hamdard Institute of Medical Sciences & Research,** Hamdard Nagar New Delhi invited Dr JS Arora on 2<sup>nd</sup> August 2019 to deliver an orientation lecture to MBBS students on Thalssemia

and Sickle cell anaemia. Dr Rekha Harish ex Professor & Head Department of Government Medical College organized this activity



**Thalassemia Society of Bareilly** in association with National Thalassemia Welfare Society organized a thalassemia check-up and



HLA typing camp on Sunday 4<sup>th</sup> August'2019. Around 50 patients were examined by Dr JS Arora. Total 94 samples for HLA typing were taken by NTWS Staff Gagandeep Singh, Shobri Ghosh and Aarti Yadav at a subsidized rate of Rs 1700 only per person for high resolution typing. There were 27 patients out of which 5 patients got HLA matched donor in this camp.





**Raktadata Foundation** in association with National Thalassemia Welfare Society (NTWS), Delhi organized a Thalassemia awareness seminar and check-up camp on 27<sup>th</sup> September, 2019 at Mathura, Vrindavan, UP. Dr JS Arora was a special invitee from Delhi. A CME



was organized to create awareness among doctors and paramedics at Ramakrishna Math & Ramakrishna Mission Seva Ashrama. Dr Somnath Maharaj ji presided over the meeting. Dr Arora gave a lecture



on overview of thalassemia, Dr Shaily Rajput highlighted the blood bank services available at the centre Mr Amit Goyal president Raktadata Foundation, Raya, Mathura promised to arrange blood for all thalassemic patients of Mathura. 95 units of blood were collected on that day. Secretary of the math Suprakashanand ji Maharaj promised to provide full support to thalassemia patients residing in and around Mathura Vrindavan.

**J&K Thalassemia Welfare Society, Jammu** organized a thalassemia check-up camp at Government Medical College, Jammu. On Saturday, Sunday 30<sup>th</sup> Nov' & 1<sup>st</sup> Dec'2019

Dr VP Choudhry and Dr JS Arora examined 82 patients. Medical Superintendent of the hospital, HOD Pediatrics Dr Saini and HOD Pathology Dr Koul also visited the camp. Dr Choudhry and Dr Arora apprised them the problem being faced by thalassemics in getting the adequate treatment. Dr Arora also informed them that new thalassemia patients are still being born in Jammu and requested them to sensitize gynaecologist to screen every pregnant women during her first visit for antenatal check-up on Sunday 1<sup>st</sup> Dec. IAP Jammu branch organized a



CME on Pediatrics update which was supported by Indian Journal of Pediatrics. Dr Choudhry enlightened on ABC of CBC and Dr Arora stressed on need of prevention to arrest the birth of new thalassemia



major patients. CME also covered topics on Asthma, Chronic Diarrhoea, Anemia, Child with headache and Septic shock in children, by eminent faculty from AIIMS and PGI Chandigarh

National Thalassemia Welfare Society was honoured by Deputy Director NACO, Sh. Sai Prasad Bhavsar at an All India Award Function organized by Human Social Foundation, Hanumangarh Rajasthan on 22<sup>nd</sup> September for organizing Maximum Blood donation Camps in a year and helping human beings with emergency blood requirements in Delhi-NCR. Ms Monisha Gogoi and Shobri Ghosh represented NTWS to receive the honor







To mark 550<sup>th</sup> Birth Anniversary of Guru Nanak Dev Ji a blood donation Camp was organized on 10<sup>th</sup> November at C' Block Gurudwara Vikaspuri where 85 units of blood were collected by RML Blood Bank



Delhi. On this day we also got the opportunity to sensitize the four newly married couples about thalassemia. after each Anand Karaj (phere)



Dr JS Arora also gave lecture on thalassemia and motivated newly married couples to undergo thalassemia screening as early as possible positively before conception and prevent their new generation from thalassemia.

**Indian Alliance Of Patients Group (IAPG)** in collaboration with National Thalassemia Welfare Society (NTWS) and Indian Institute of Health Management Research (IIHMR) organised an event on the first-



ever World Patient Safety Day on 17 September 2019 at IIHMR campus in Dwarka, Delhi to commemorate the global campaign

launched by WHO to create awareness on patient safety and urge people to show their commitment of making healthcare safer. It was inaugurated by the chief guest, Dr Dhananjay Sable (Assist. Drugs Controller India) in presence of Dr Sanjeev Kumar chairperson of IAPG and the General Secretary of NTWS, Dr JS Arora (Member of Advisory Group PFPS WHO). Many distinguished doctors and care givers attended the event and spoke on patient safety.

Dr Anjana Bhushan, Regional Advisor, Health Systems Development, WHO, presented a well versed detailed allocation of Patient Safety, from WHO perspective and mission. She also played the video message of Director General of WHO on the occasion of the launch of 1st World Patient Safety Day. She apprised the importance of Universal Health



Coverage. Dr RN Makroo, an authority on Transfusion medicine, deliberated his talk on the congruent approach to blood supply and blood safety. He discussed the status of Transfusion Transmitted Infection in India, which includes HIV, HCV and HBV. He also discussed the role of Nucleic Acid Testing in ensuring the Patients



Safety and concluded his talk with the need of rational use of blood components. Dr Inder Prakash (Advisor Public Health) Director General of Health Services, Ministry of Health & FW, Government of India) comprehended the perspective of policy making by measuring Quality of Care given to the patients, data collection, data analysis,





incident responses, remedies and feedback, patient safety campaigns and involvement of Patients Safety Organisations in making Policies for the Safety of Patients, a part of global burden in India.

The event urged to raise awareness of the need for regular blood donations to ensure that all individuals and communities have access to affordable and timely supplies of safe and quality assured blood and blood products, as an integral part of Universal Health Coverage.



Dr JS Arora submitting the list of necessary steps recommended by WHO to mark the 1st World Patient Safety Day 17th September 2019 to Mr. Manish Sisodia Hon'ble Deputy Chief Minister of Delhi



of Mr Amit Khatri Deputy Commissioner Gurugram was chief guest and Secretary Red Cross Gurugram was guest of honour. Mrs Monisha Gogoi & Gagandeep Singh from NTWS also participated



NTWS Team participated for the 11<sup>th</sup> year at Airtel Delhi Half Marathon 2019 on 20<sup>th</sup> October. Ms. Monisha Gogoi was awarded 2<sup>nd</sup> highest Fund raiser in 'I Care' category raising Rs.5,33,200/-.



NTWS raised Rs. 9,99,162 lacs during ADHM 2019. Ms. Monisha Gogoi with Mr. Anil Bajjal, Lieutenant Governor of Delhi.

G D Goenka Allied Medical Sciences Gurgaon invited Dr JS Arora to give a talk on Thalassemia on 16<sup>th</sup> Oct 2019. Smt Krishna Devi mother

NTWS participated World Disability Day celebration at India Gate on 3<sup>rd</sup> December, along with the other Disabilities. Arushi Mishra Thalassemia Major performed Kathak Bollywood dance style at this great platform of India Gate.



On 18<sup>th</sup> August NTWS Team celebrated the 92<sup>nd</sup> Birthday of our President Km. Surrender Saini at her residence.



Sunday 23d June 2019, Blood Patients Protection Council, (BPPC) Kerala, organized world Sick cell day and get together of blood disorder patients at The Regional Science Center, Calicut. Mukkam Muhammed, standing committee chairman of health, Calicut district panchayat inaugurated the program. Dr. Manash Bagchi, Director of Regional Science center presided over the function. He also presented a memento and cash prize to A.P. Anas who passed B-Tech examination is the first Thalassemia patient achieved B-Tech in Kerala. Dr. Roshan Bijlee, Director, Composite Regional Center for the person with



disabilities, took a lecture about special privileges of blood disorder patients in the disability Act.2016.



Kareem Karassery, State Gen. Convener of Blood Patients Protection Council welcomed the gathering, distributed free umbrella to all patients and also submitted a memorandum to A.Pradeep Kumar MLA for sanctioning blood filter set, chelating drugs, and expert treatment center to all the blood disorder patients without considering their age and economical level.

Due to lockdown World Thalassemia Day was observed at home in Kerala. Related to this a banner was raised at Phoenix Sailam. Kareem Karassery state Gen. Convener of the Blood Patients Protection council



appreciated the work done by Fire and rescue services and Kerala police to distribute chelating drugs and Leucocyte filter set from Medical college hospital to the residence of Thalassemia patients. Blood patients Protection Council thanked to all the youth organisation those who came to donate blood to Thalassemia patients and other needy.

Thalassemia and Sickle Cell Society is established in 1998 with a vision to take care of Thalassemia and Sickle Cell Anemia patients in Hyderabad, Telangana. With the aim to provide appropriate treatment and achieve a good quality of life for every patient with Hemoglobinopathies and to encourage prevention policies thus of reducing the number of new births with thalassemia. At present 2740

(18 May 2020) children are registered with our society.

## Activities of TSCS 1<sup>st</sup> Jan – 15<sup>th</sup> May 2020



- 44 new patients were registered with our society including 30 Thalassemia Major, 10 Sickle Cell Anemia, 3 Sickle Beta Thalassemia and 1 Thalassemia Intermedia.
- 69 camps were conducted during the period
- 5934 number of units blood collected during the period and 4972 units of blood given to 4389 Thalassemia and Sickle Cell patients.
- All the patients were provided with travel pass to come for regular transfusion without any hassles.
- Due to COVID 19 pandemic blood was collected through in-house donations during the month of March and April to support our patients.
- With support from Government of Telangana small camps could be organised during the month of May to overcome the scarcity of blood due to COVID 19.
- We are very much thankful to Health ministry, Police department and all the donors for coming forward to support our patients in these tough times.
- Breakfast and lunch was provided to all the patients and their attenders free of cost during the lockdown period by various sponsors.



Society has taken all the precautionary measures to prevent



COVID 19 by following sanitation measures, maintaining social distancing, providing masks, giving preventive medicine to all the staff members and patients.

- All the patients were made aware of preventive measures of COVID 19 through telephonic messages, WhatsApp messages, pamphlets, posters etc.
- On occasion of World Thalassemia Day on 8<sup>th</sup> May, Mr Chandrakant Agarwal, President and other Board Members distributed fruits and biscuits to our children.
- The society was visited by many eminent officers including Honorable Justice Challa Kodandaram, Dr. Lavanya NJP, Additional Deputy Commissioner of Police, Cyberabad, Ms Chandrakala, RDO along with Dasari Srinivas Retd. IAS (Special Chief Secretary). They were very much pleased with our services.

Dr JS Arora presenting a memorandum to Hon'ble Minister of Health Dr Harsh Vardhan on 14th June 2019



Lovish and sarthak playing guitar and singing song on occasion of world blood donors day 14th June 2019 at MAMC auditorium

Dr JS Arora visited Hon'ble Minister of Health Govt. of Delhi Sh. Satyendra Jain along with patients of Chacha Nehru Bal Chikitsalya to apprise him the problems faced by thalassemia patients over there.



Every year under its Social Innovation Program, SCHOOL of INSPIRED LEADERSHIP (SOIL) deputs 4 student volunteers at NTWS. These volunteers work every Wednesday for almost one year



and help us in creating awareness, organizing blood donation camps and raising funds. Dr JS Arora & Aarti Yadav visited SOIL in Nov'2019 to review their activities in the midterm.

Dr JS Arora was invited for international consultation by Indian Social Institute on "Human Rights of Person with Disability" on 17th Jan'2020 at Indian Social Institute, Institutional Area, Lodhi Road, New Delhi to give a lecture on "Rights of Person with Disability Act vis-a-vis Blood Disorders





Dr JS Arora was invited by NCPEDP for NDN/NCRPD members Meeting on the status of the implementation of the RPWD Act 2016. in Delhi on 16th of January, 2020 at Residency Resorts Pvt Ltd, USI Premises, Shankar Vihar, New Delhi.



Panipat Thalassemia Welfare Society which was formed recently in Jan'2020 organized it's first ever clinical meeting on Sunday 19th Jan 2020 at SD Vidhya Mandir School Panipat. Dr Shashi Garg Deputy CMO was Chief Guest, guest of Honors were IMA President Dr Anjali,



gynecologist Dr Manisha and Dr Gaurav Srivastava. In his opening remarks Dr JS Arora appraised the audience current situation of thalassemia in Panipat, where patients have to travel over 100 Km to Rohtak or Delhi for basic treatment like transfusion and chelation. He requested Deputy CMO to make transfusion facilities including



packed RBCs (leuco reduced or with bed side filters) and all three chelator available in panipat at Civil Hospital. He also stressed the need of thalassemia screening in pregnant women and appealed to deputy CMO, Dr Shashi Garg, IMA President Dr Anjali and other guests to sensitize the gynecologists to take effective measures to control thalassemia. Dr VP Choudhary answered the questions raised by the patients and parents. Dr Shashi Garg in her address said chelating agents are available and any patient even if he or she is going to a

private hospital, nursing home for transfusion can contact her directly for getting chelating agents.



Dr Arora and Dr Choudhry examined and advised treatment around 50 patients. Mr. Vikrant Mahajan and Treasurer Mr. Jatin Makkar thanked Dr JS Arora, Dr VP Choudhry, Dr Shashi Garg and other guests for being there to support the cause and assured patients and parents that he will always be there to help them.

Indian Red Cross Society Gurgaon branch organised a blood donation camp and seminar on de-addiction on Friday 24th Jan'2020 at ITI Gurgaon. Chief guest was MLA Sudhir Singla and Guest of honour Smt Krishna Devi mother of Mr Amit Khatri Deputy Commissioner



Gurgaon. Dr JS Arora was invited to deliver a lecture on Thalassemia, Blood Donation and De-addiction he was honoured with a shawl and mala for his contribution to the society. The event was presided over by Secretary Red Cross Gurgaon Mr Mahesh Gupta and conducted by Mr Suresh Gupta it was attended by ITI students, local population and personalities representing various social organizations in Gurgaon





# NTWS Blood Donation Camps January 2019 to June 2020

**NTWS Collected more than 5000 thousand units of blood  
by organizing blood donation camps from January 2019 to June 2020**

Date	Organised at Venue	Blood Bank	Date	Organised at Venue	Blood Bank
26-01-19	Tecnia Sai Auditorium Rohini	DDU	28-06-19	Aegis Dentsu, Gurgaon	RML
04-02-19	Anarock, Gurgaon	DDU	03-07-19	Bambino Agro Industries, Gurgaon	DDU
04-02-19	Anarock, Ghaziabad	LHMC	15-07-19	Dun & Bradstreet, Okhla	RML
05-02-19	Anarock, Noida	RML	15-07-19	HPCL, Bahadurgarh	PGLRohtak
16-02-19	Axis Bank, Noida	RML	15-07-19	HPCL, Laxmi Nagar	DDU
18-02-19	Oriental Bank of Commerce, Gurgaon	RML	15-07-19	HPCL, Tikri Kalan	BSA
19-02-19	Oriental Bank of Commerce, Faridabad	AIIMS	26-07-19	DTDC, Sector-18, Gurgaon	RML
21-02-19	Haryana Roadways, GGN	DDU	26-07-19	DTDC, Samalkha	Red Cross
22-02-19	Iris Tech Park, Gurgaon	RML	08-08-19	IIC Project, Dwarka	DDU
06-03-19	College of Vocational Studies, Malviya Nagar	RML	09-08-19	Edelweiss, Mercantile House, CP	RML
07-03-19	Bechtel India, Gurgaon	DDU	09-08-19	Edelweiss, B'Block, Cannaught Place	LHMC
08-03-19	DLF Emporio & Promenade, Vasant Kunj	RML	12-08-19	Awfis, Cyber Park, Gurgaon	LHMC
14-03-19	IITM Janakuri	LHMC	13-08-19	Awfis, Sector-44, Gurgaon	DDU
19-03-19	SOIL, Gurgaon	DDU	13-08-19	Awfis, Ambience Island	LHMC
03-05-19	HSBC Bank, Gurgaon	DDU	13-08-19	Nukleus Co- work, Noida	RML
10-05-19	Tata Capital Housing Finance, New Delhi	LHMC	14-08-19	SISL Infotech, Delhi	LHMC
10-05-19	Tata Capitals, Lajpat Nagar, Delhi	LHMC	04-09-19	Fluor Daniel, Gurgaon	DDU
10-05-19	Tata Capitals, Jhandewala, Delhi	RML	04-09-19	Fluor Daniel, Gurgaon	LHMC
22-05-19	WNS Global Services, Noida	RML	04-09-19	Fluor Daniel, Gurgaon	RML
23-05-19	WNS Global Services, Gurgaon	DDU	05-09-19	Fluor Daniel, Gurgaon	AIIMS
24-05-19	WNS Global Services, Gurgaon	RML	05-09-19	Fluor Daniel, Gurgaon	LHMC
02-06-19	Rajput Co-operative Assoc. Dabri	RML	13-09-19	Sterlite, Gurgaon	RML
07-06-19	C' Block, Gurudwara, Vikaspuri	BSA	15-09-19	Talent Hunt Dance & Music Academy Gurgaon	DDU
14-06-19	Vatika Triangle, Gurgaon	DDU	18-09-19	HSBC, Sector-18, Noida	RML
15-06-19	IDFC Bank, Rajendra Place	RML	19-09-19	HSBC Bank, JMD Gurgaon	DDU
15-06-19	IDFC Bank, Orchid Business Park, Gurgaon	DDU	20-09-19	KPMG, Noida	LHMC
15-06-19	Chola Mangalam, Pusa Road	BSA	20-09-19	HSBC Bank, Corporate office, Gurgn	RML
15-06-19	IDFC Bank, ITO	LHMC	04-10-19	Gillette India, Bhiwadi	RML
16-06-19	Arora Polyclinic, Vikaspuri	DDU	01-10-19	DME, Noida	LHMC
18-06-19	Vatika First India Place, Gurgaon	DDU	12-10-19	J&K Business School, Damdama Lake	RML
19-06-19	Vatika City Point, Gurgaon	DDU	18-10-19	Axtria, Gurgaon	RML
20-06-19	Vatika Atrium, Gurgaon	DDU	10-11-19	C' Block Gurudwara, Vikaspuri	RML
21-06-19	Vatika Tower, Gurgaon	RML	15-11-19	SPM Autocomp Services, Manesar	DDU
25-06-19	Vatika Professional Point, Gurgaon	DDU	18-11-19	Wazirpur Market Association, Bhajanpura	RML
26-06-19	Vatika Mindscape, Faridabad	RML	19-11-19	Ciena India, Gurgaon	DDU
27-06-19	Vatika Business Park, Gurgaon	DDU	27-11-19	Luminuos, Gurgaon	RML
			29-11-19	Axis House, Gurgaon	RML
			08-12-19	Nirvana Country, Gurgaon	RML
			11-12-19	Wipro Ltd., Sarita Vihar	DDU
			12-12-19	Vatika Business Park, Gurgaon	RML



# NTWS Blood Donation Camps January 2019 to June, 2020

12-01-2020	Teesra Pusta, Usmanpur	RML
18-01-2020	Udgam Pre School, Noida	RML
22-01-2020	SOI L, Gurgaon	DDU
05-02-2020	Fedex Express, Aerocity	DDU
05-02-2020	Fedex Express, Okhla	LHMC
05-02-2020	Fedex Express, Gurgaon	RML
10-02-2020	Anarock Property Consultancy Pvt. Ltd. Trade Tower, Noida	RML
10-02-2020	Anarock Property Consultancy Pvt. Ltd. Zygon Square Noida	GTB
10-02-2020	Anarock Property Consultancy Pvt. Ltd. 9B DLF Phase-3 Gurgaon	DDU
10-02-2020	Anarock Property Consultancy Pvt. Ltd. Sector-32 Gurgaon.	LHMC

13-02-2020	RBL Bank, Okhla	LHMC
13-02-2020	RBL Bank, Noida	RML
13-02-2020	RBL Bank, Cannaught Place	DDU
14-02-2020	RBL Bank, JMD Metropolis, GGN	DDU
03-03-2020	Fostiima Management Institute Dwarka	DDU
06-03-2020	DLF Promenade Mall, Vasant Kunj	DDU
10-03-2020	Bechtel India Pvt. Ltd, Gurgaon	RML
29-04-2020	Arora Polyclinic, Vikaspuri	DDU
21-06-2020	Arora Polyclinic, Vikaspuri	DDU

## Blood Donation Camps Organized By NTWS 2019 - 2020





## Assam News

World Thalassemia Day 2020 and COVID 19 pandemic @ Clinical Hematology Guwahati Medical College Hospital (GMCH) Assam. Creating Awareness Creating Positivity.....on 8th May 2020



North East Thalassemia Welfare Society Dibrugarh, Assam celebrating the International Thalassemia Day 2020 amidst Corona scare with few patients who came for Blood transfusions at AMC Hospital, Dibrugarh. Dr Aditi Barua have made some masks and distributed amongst the patients and the parents.

# NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018

[www.thalassemiaindia.org](http://www.thalassemiaindia.org), E-mail : [ntws2019@gmail.com](mailto:ntws2019@gmail.com)

## Special Subsidised Rates for Poor Thalassemics Registered with NTWS

### Medicines & Equipments

Asunra	400mg	100mg	Oleptiss	360mg	180mg	90mg
Desirox	500mg	250mg	Deferijet FCT	360mg	180mg	90mg
Desferal	0.5g		Leucocyte filters			
Deferijet	500mg	250mg	Infusion Pumps			
Desifer	400mg	100mg	Scalp Vein Set			
Kelfer	500mg	250mg				

### Medicine Distribution Centre :

Shop No. 101, First Floor, Gupta Tower-I, Near Mother Dairy, Sonia PVR Commercial Area, G-Block, Vikas Puri, New Delhi-18 Mob. 9311166710 / 711 / 712, 9811420713, Ph. 011-42316079

## NTWS Thalassemia Centre

Free Thalassemia Clinic, 2<sup>nd</sup> Sunday every month

Registration time : 9am to 12 noon

### Address

NTWS Thalassemia Centre,  
2<sup>nd</sup> Floor, Community Centre, DUSIB,  
Above Voter ID & Ration Card office,  
Near Gurudwara Singh Sabha,  
Block-12, Tilak Nagar, New Delhi-110018  
Ph.: 9311166710-711-712 & 9811420713

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Any person can become Member of the Society by filling up the requisite form and sending a DD in favour of :

### National Thalassemia Welfare Society

Form can be download from [website : www.thalassemiaindia.org](http://www.thalassemiaindia.org)

<b>Life Member</b>	<b>Indian</b>	<b>INR</b>	<b>500</b>
	<b>NRI/Foreigner</b>	<b>USD</b>	<b>100</b>
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	<b>NRI/Foreigner</b>	<b>USD</b>	<b>1,000</b>
<b>Patron</b>	<b>Indian</b>	<b>INR</b>	<b>50,000</b>
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# थैलासीमिया चिकित्सा सम्बन्धी आवश्यक जानकारी

1. हमेशा Hb 10g/dl से अधिक रखें अर्थात् जैसे ही Hb 10g/dl पहुंचता है तभी खून चढ़ा दें।
2. रेडक्रास ब्लड बैंक तथा सभी सरकारी अस्पतालों के ब्लड बैंक में थैलासीमिया रोगियों के लिए निःशुल्क रक्त की व्यवस्था है।
3. Leucodepleted Packed RBCs चढ़ाने चाहिये अथवा Leucocyte Filter का प्रयोग करें।
4. पहली बार रक्त चढ़ाने से पहले हैपेटाईटिस-बी प्रतिरोधक सूई अवश्य लगवा लें। यदि अभी तक न लगवाई हो तो तुरन्त लगवा लें। हर पाँच वर्ष पश्चात हैपेटाईटिस-बी प्रतिरोधक सूई पुनः अवश्य लगवायें।
5. लगभग 12-15 बार खून चढ़ाने के बाद Ferritin की जांच कराएं। यदि Ferritin 1000 ng/ml से अधिक है तो लोहा निकालने की दवा Desferal, Kelfer अथवा DEFRAIROX चिकित्सक के परामर्श अनुसार जल्द से जल्द आरम्भ करें।
6. वर्ष में चार बार Ferritin की जांच आवश्यक है।
7. Ferritin हमेशा 1000 ng/ml से कम रखने का प्रयास करें। यदि Ferritin 500-800 ng/ml रखें तो अच्छा है।
8. 10 वर्ष की आयु पश्चात प्रति वर्ष MRI T<sub>2</sub>\* करवाना उपयोगी है।
9. Desferal Infusion Pump की सहायता से धीरे-धीरे 10-12 घंटे में दें और पम्प स्टार्ट होने के आधे घंटे के बाद 50-100mg Vitamin C की गोली अवश्य दें और इससे अधिक कभी न दें।
10. Desferal Injection कभी भी Blood Bag में मिक्स ना करें।
11. Kelfer अथवा Hydrea प्रयोग करते समय प्रति 3-4 सप्ताह Hb, TLC, DLC, Platelet की जांच अवश्य करायें। हर बार बुखार, गला खराब आदि रोग होने पर उपयुक्त जांच पुनः अवश्य करायें।  
यदि TLC 3000 से कम अथवा Polymorph - Neutrophil Count 1000 से कम अथवा Platelet 1,00,000 से कम हो तो तुरन्त दवा बन्द कर दें और अपने थैलासीमिया संबंधी चिकित्सक से अवश्य संपर्क करें।
12. थैलासीमिया रोगी को हरे पत्ते की सब्जियां, गुड़, बकरे का मांस, कलेजी, गुर्दे, कपूरे आदि बिल्कुल न दें और प्रत्येक भोजन पश्चात् चाय दें।
13. 18 वर्ष की आयु पश्चात प्रति वर्ष DEXA SCAN करवाना उपयोगी है।
14. रोगी को रोज अनार, पालक या चुकन्दर का रस न दें, कभी-कभी अनार के दाने, पालक का साग खाने में कोई हर्ज नहीं है।
15. किसी प्रकार का (एलोपैथिक, आयुर्वेदिक, यूनानी या होम्योपैथिक) दवा जिसमें लोहा हो, नहीं लेना चाहिये।
16. किसी भी खाद्य पदार्थ को लोहे के बर्तन में न तो रखें और न ही पकायें।
17. भोजन में अनाज दूध, दूध से बने पदार्थ, दालें, सोयाबीन व मटर का प्रयोग अधिक करें।
18. अपने संबंधियों एवम् मित्रों को थैलासीमिया जांच तथा Blood Donation के लिए प्रेरित करें।
19. थैलासीमिया रोगी को उनके सगे भाई-बहन समान पूरा ध्यान दें, न अधिक न कम।
20. थैलासीमिया बच्चे का HLA match जल्द से जल्द सगे भाई-बहन से करवा लें।

## DEFRAIROX-ASUNRA/DESIROX/DEFRIJET/OLEPTISS

का प्रयोग करते समय निम्न बातों का ध्यान आवश्यक है।

1. दवा प्रारम्भ करने से पहले तथा पुनः हर महीने UREA, CREATININE, SGOT, SGPT, BILLIRUBIN, TOTAL DIRECT, URINE ALBUMIN तथा CBC (Hb, TLC, DLC, Platelet) की जांच आवश्यक है।
2. दवा को खाली पेट खाने से आधा घंटा पहले 100-200ml पानी, संतरे या सेव के जूस में हिला कर लेना चाहिए। साबुत या चबा कर नहीं खाना चाहिए। गिलास में बची हुई दवा को पुनः थोड़े पानी में हिलाकर पी लेना चाहिए।
3. शरीर पर चकत्ते अथवा अतिसार (Diarrhoea) होने से घबराने की आवश्यकता नहीं, थैलासीमिया चिकित्सक से सम्पर्क करें।
4. Oleptiss तथा Defrijet FCT को साबुत ही निगलना होता है। इनको खाना खाने के उपरान्त भी लिया जा सकता है।