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International Thalassemia Day 2019

"Universal Access to Quality Thalassemia Healthcare Services:
Building Bridges With and For Patients"

Thalassemia Meet

Health, Wealth & Family

Sunday, 5th May 2019

Constitutional Club, New Delhi



National Thalassemia Welfare Society

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Dignitaries on the dais from left to right Dr. SK Arora, Additional DHS Govt. of Delhi, Mr. TD Dhariyal, Commissioner Disabilities, Govt. of Delhi, Mrs. Vinita Srivastava, National Senior Consultant & Co-ordinator Blood Cell-NHM, Dr. VP Choudhry, Former Professor and Head Department of Haematology AIIMS, Delhi and Dr. VK Khanna, Chairman, Department of Pediatrics, Institute of Child Health, Sir Ganga Ram Hospital, New Delhi.

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federation of indian thalassemics

Blood Transfusion Services and Role of E-Rakt Kosh:

National Health Mission (NHM) has recently taken numerous steps towards a comprehensive and total quality management approach for blood services by providing the technical and financial assistance to the States/UTs to modernize their blood banks.

Ministry of Health and Family Welfare (MH&FW) has set up a Blood cell under NHM to ensure the accessibility, adequacy, safety and quality of blood and **prevention & control of Haemoglobinopathies and initiate stem cell registry.**

"E-Rakt Kosh" portal has been developed by NHM along with National Institute of Biologicals for strengthening of blood services and to improve the standards of blood services in the country.

"E-Rakt Kosh" a Centralized Blood Bank Management Information System has been conceptualized and developed as a comprehensive IT solution for streamlining the workflow of blood banks across the country as per standard operating procedures.

The major concern of Blood Banks is to ensure efficient and safe collection and maintenance of quality blood stock. There is a need to phase out replacement donation and curb the malpractices of professional/paid donations. **'E-Rakt Kosh'** is an attempt to address these problems by providing means to connect, digitize and streamline the work flow of blood banks in India. Objective is to revise the existing systems, to bring some process re-engineering and to automate data entry, search and accessibility. These electronic processes will help the public to easily access the blood availability status and can make requisition of a particular blood group specific blood component in nearby blood banks (especially rare groups). Online tracking and trailing system of the blood and blood products (components of blood), by the state level administrators will also be possible.

Some of the important features of the system are:

- Real time blood stock availability to the service providers and beneficiaries.
- Minimize wastage of blood due to expiry.
- Restrict professional blood donors and ensure donation of quality blood by introducing biometrics.
- Networking of Blood Banks.
- Blood Donor and Camp management.
- Enable to create State-wise / District-wise donor repository.
- Mobile based application for administrators, service providers and end users.
- Donor registration details, donor counseling, physical examination, donation details etc.
- Investigation details of donor sample while maintaining confidentiality in case the tests results are positive.
- E Rakt Kosh captures details of thalassemia patient, raises it's blood component request and displays blood requirement details of registered thalassemia patients.

रक्त आधान सेवाएं और ई- रक्त कोष की भूमिका

राष्ट्रीय स्वास्थ्य मिशन (एनएचएम) ने हाल ही में अपने रक्त बैंकों के आधुनिकीकरण के लिए राज्यों / संघ राज्य क्षेत्रों को तकनीकी और वित्तीय सहायता प्रदान करके रक्त सेवाओं के लिए एक व्यापक और समग्र गुणवत्ता प्रबंधन दृष्टिकोण की दिशा में कई कदम उठाए हैं।

स्वास्थ्य और परिवार कल्याण मंत्रालय (MH&FW) ने एनएचएम के तहत रक्त कोशिका की स्थापना की है, जिससे रक्त की गुणवत्ता, पहुंच और सुरक्षा एवं हेमोग्लोबिनोपैथी की रोकथाम और नियंत्रण तथा स्टेम सेल रजिस्ट्री की उपलब्धता सुनिश्चित की जा सके।

"ई- रक्त कोष" पोर्टल को राष्ट्रीय स्वास्थ्य मिशन (एनएचएम) ने राष्ट्रीय जैविक संस्थान के साथ मिलकर राष्ट्रीय रक्त सेवाओं की मजबूती के लिए और देश में रक्त सेवाओं के मानकों को बेहतर बनाने के लिए विकसित किया है।

"ई- रक्त कोष" एक केंद्रीयकृत ब्लड बैंक प्रबंधन सूचना प्रणाली है जिसको मानक संचालन प्रक्रियाओं के अनुसार देश भर में ब्लड बैंकों के कार्य को सुव्यवस्थित करने के लिए एक व्यापक सूचना प्रौद्योगिकी समाधान के रूप में संकल्पित और विकसित किया गया है।

रक्त बैंकों की प्रमुख चिंता प्रभावशाली और सुरक्षित रक्त संग्रह और गुणवत्ता वाले रक्त भंडार के रखरखाव को सुनिश्चित करना है। प्रतिस्थापन रक्त दान को चरणबद्ध क्रम से समाप्त करना और पेशेवर / भुगतान किए गए रक्त दान के दुराचार पर अंकुश लगाने की आवश्यकता है। **"ई- रक्त कोष"** भारत में ब्लड बैंकों के कार्य प्रवाह को जोड़ने, डिजिटाइज़ करने और उन्हें सुव्यवस्थित करने के साधन उपलब्ध कराकर इन समस्याओं को दूर करने का एक प्रयास है। उद्देश्य मौजूदा सिस्टम को संशोधित करना है, कुछ प्रक्रियाओं को फिर से पुनः योजना में लाना है और आंकड़ों की प्रविष्टि, खोज और पहुंच को स्वचालित करना है। ये इलेक्ट्रॉनिक प्रक्रियाएं जनता को आसानी से रक्त की उपलब्धता स्थिति जानने में मदद करेंगी और निकटम रक्त बैंकों (विशेष रूप से दुर्लभ समूहों) में एक विशेष रक्त समूह, विशिष्ट रक्त घटक की प्रार्थना करने में मददगार साबित हो सकती है। राज्य स्तर के प्रशासकों द्वारा रक्त और रक्त उत्पादों (रक्त के घटक) की ऑनलाइन ट्रैकिंग और अनुगामी व्यवस्था भी संभव होगी।

प्रणाली की कुछ महत्वपूर्ण विशेषताएं-

- सेवा प्रदाताओं और लाभार्थियों को वास्तविक समय में रक्त संग्रह की उपलब्धता
- अंतिम तिथि से होने वाली रक्त की क्षति को कम करना
- पेशेवर रक्त दाताओं को प्रतिबंधित करना और बायोमेट्रिक्स शुरू करके गुणवत्ता वाले रक्त का दान सुनिश्चित करना
- ब्लड बैंकों की नेटवर्किंग
- रक्त दाता और शिविर प्रबंधन
- राज्यवार / जिलेवार दाता भंडार बनाने में सक्षम बनाना
- प्रशासकों, सेवा प्रदाताओं और अंतिम उपयोगकर्ताओं के लिए मोबाइल आधारित अनुप्रयोग
- रक्त दाता पंजीकरण विवरण, रक्त दाता परामर्श, शारीरिक परीक्षा, रक्त दान विवरण आदि परीक्षण के परिणाम सकारात्मक होने की स्थिति में गोपनीयता बनाए रखते हुए दाता नमूने की जांच
- **"ई- रक्त कोष"** थैलेसीमिया रोगी के विवरणों को अभिग्रहण करता है, यह रक्त के घटक का अनुरोध और पंजीकृत थैलेसीमिया रोगियों के रक्त की आवश्यकता के विवरण को प्रदर्शित करता है।

Fertility and Pregnancy in Women with Thalassemia Major and Intermedia

Beta thalassemia is a hemoglobinopathy characterized by decreased production of beta globin chains causing alpha globin chains to accumulate and aggregate. This results in inadequate haemoglobin production. There is microcytic hypochromic anemia, ineffective erythropoiesis and hemolytic anemia. Diagnosis is made by detecting low HbA and increased HbA2 and HbF.

Types

- thalassemia minor/ trait: mild or no anemia.
- thalassemia major (BTM): severe form, only HbA2 and F detected. Severe anemia, transfusion dependent and develop complications of iron overload.
- thalassemia intermedia (BTI): present late in life, mild anemia, not transfusion dependent, may develop iron overload.

Fertility

BTM: infertility or subfertility is due to iron deposition in endocrine organs. Direct iron deposition occurs in hypothalamus and pituitary and ovaries. Iron deposition leads to organ damage through oxidative stress.

Majority of patients are infertile due to hypothalamic hypogonadism, associated with amenorrhoea, anovulation and infertility. Ovarian functions are usually preserved. These women require ovulation induction with gonadotropins to conceive. Spontaneous pregnancy can occur in well chelated and transfused patient.

Pregnancy management

Thalassemia intermedia

Spontaneous conception and successful pregnancies occur but pregnancies are associated with complications.

Chronic anemia leads to abortions, preterm labour and intrauterine growth restriction. Endocrine complications due to hemosiderosis can occur, though less common compared to BTM.

In a large study which included 83 pregnancies in 44 women, 20.5% ended in abortion, 77.1% had live births and 2 had intrauterine death. Mean gestational age at delivery was 36.5 weeks and birth weight 2551gms. Cesarean section rate was 72.7%. 79.5% women required blood transfusions and 27.3% required transfusion for first time. There was increase in average ferritin levels before and after pregnancy.

Patients with BTI have increased incidence of thrombotic events.

Thalassemia Major

Aggressive transfusion and iron chelation therapy has improved life expectancy and fertility with decrease in medical disability. Many cases of successful pregnancy have been reported. These pregnancies need to be monitored carefully to avoid adverse outcome.

Preconception evaluation

- Transfusion needs
- Compliance with chelation
- Iron load status
- Indirect coomb's test
- Screen for infections-HIV, Hepatitis B and C
- Assess end organ damage from iron overload
- Genetic evaluation of partner and need for prenatal testing

Adverse effect on pregnancy depends on

- Presence of alloimmune antibodies
- Cardiac dysfunction
- Severe diabetes mellitus
- Liver dysfunction
- Active hepatitis/HIV
- Significant enlargement of spleen

Prenatal care

- Folic acid
- Interdisciplinary team
- Ferritin levels and blood counts
- Blood transfusions to maintain Hb 10g/dl
- Cardiac, endocrine, hepatic function at initial visit and repeat in each trimester
- Screen for diabetes and hypothyroidism
- Fetal growth and well being
- Iron chelating agents to be stopped in pregnancy.

In a recent large series of 58 pregnant women with BTM, intrauterine growth restriction and preterm delivery occurred in 40%, 15% developed IGT/abnormal GTT, there was increased need for transfusion, there was 60% increase in baseline ferritin. There were many twin pregnancies as most women conceived on ovulation induction using gonadotropins.

Cardiac involvement and arrhythmias are important cause of morbidity and death.

Delivery: route of delivery as per obstetric indications. Cesarean section rates are high because of cephalopelvic disproportion due to short stature or other pregnancy related complications.

Dr. Vatsla Dadhwal

Professor Division of maternal fetal medicine department of Obs. & Gynaec., AIIMS New Delhi

Fetal medicine : Diagnostic and therapeutic interventions including intrauterine transfusions, interventions in complicated twins

High risk pregnancy

Nodal officer for PPTCT programme

Chairperson AOGD Fetal Medicine subcommittee 2017-19



Dr. Vatsla Dadhwal

बीटा थैलेसीमिया एक रक्तविकार है जिसमें बीटा ग्लोबिन श्रृंखलाओं के उत्पादन में कमी होती है, जिसके कारण अल्फा ग्लोबिन श्रृंखलाएं एकत्रित हो कर समूह बना लेती हैं। इसके परिणामस्वरूप हीमोग्लोबिन का अपर्याप्त उत्पादन होता है। इससे Microcytic Hypochromic एनीमिया, अप्रभावी एरिथ्रोपोएसिस और हिमोलिटिक एनीमिया होता है। इसका निदान कम HbA_{1c}, बढ़े हुए HbA₂ और HbF का पता लगाकर किया जाता है।

प्रकार

थैलेसीमिया वाहक लक्षण: हल्का या कोई एनीमिया नहीं।

थैलासीमिया मेजर (बीटीएम): गंभीर रूप, रक्त जांच में केवल एचबीए 2 और एचबी का पता चलना। गंभीर रक्ताल्पता, रक्ताधान पर निर्भरता और लोहे के अधिभार की जटिलताओं का होना।

थैलासीमिया इंटरमीडिया (बीटीआई): लक्षणों की देर से प्रस्तुति, अल्प एनीमिया, रक्ताधान पर निर्भर नहीं, शरीर में अतिरिक्त लोहा जमा हो सकता है अतः लोह अतिभार से होने वाली समस्याएं भी हो सकती हैं।

प्रजननता

थैलासीमिया मेजर: बांझपन या उपप्रजनन अंतःस्त्री अंगों में लोहे के जमाव के कारण होती है। प्रत्यक्ष लोहे का संचय हाइपोथैलेमिस, पिट्यूटरी और अंडाशय में होता है। लोहे के जमाव से ऑक्सीडेटिव प्रक्रिया के माध्यम से अंगों को नुकसान होता है।

अधिकांश रोगियों में बांझपन का कारण हाइपोथैलेमिक हाइपोगोनाडिज्म की वजह से मासिक स्राव का न होना, तथा अंडे का न बनना है। डिम्बग्रंथि के कार्य आमतौर पर संरक्षित होते हैं। इन महिलाओं को गर्भ धारण करने के लिए गोर्नैडोट्रोपिंस हॉर्मोन्स के साथ ओव्यूलेशन प्रेरण की आवश्यकता होती है।

अच्छी तरह से रक्ताधान और लोह निवृत्त रोगियों में सहज ही गर्भावस्था हो सकती है।

गर्भावस्था प्रबंधन

थैलासीमिया इंटरमीडिया

गर्भाधान सहज और सफल होते हैं लेकिन गर्भधारण जटिलताओं से जुड़ा होता है।

दीर्घकालिक एनीमिया से गर्भपात, पूर्व प्रसव और अंतर्गर्भाशयी विकास अवरुद्ध होता है। लोह अतिभार के कारण अंतःस्त्री जटिलताएं हो सकती हैं, हालांकि थैलासीमिया मेजर की तुलना में कम पाई जाती है।

एक बड़े अध्ययन में, जिसमें 44 महिलाओं में 83 गर्भधारण शामिल थे, 20.5% गर्भपात हुए, 77.1% में जीवित जन्म हुआ और 2 में अंतर्गर्भाशयी मृत्यु थी। प्रसव के समय मध्यम गर्भकालीन आयु 36.5 सप्ताह और जन्म के समय वजन 2551 ग्राम था। सिजेरियन सेक्शन की दर 72.7% थी। 79.5% महिलाओं को रक्त संचार की आवश्यकता होती है और 27.3% में पहली बार रक्ताधान की आवश्यकता हुई। गर्भावस्था से पहले और बाद में औसत फेरिटिन के स्तर में

वृद्धि हुई थी।

थैलासीमिया इंटरमीडिया के रोगियों में थ्रोम्बोटिक घटनाओं की वृद्धि हुई।

थैलासीमिया मेजर

अति महत्वाकांक्षी रक्ताधान और लोह निष्कासक चिकित्सा से विकलांगता में कमी के साथ दीर्घायु की आशा और प्रजनन क्षमता में सुधार हुआ है। सफल गर्भावस्था के कई मामले सामने आए हैं। प्रतिकूल परिणामों से बचाव के लिए निम्न गर्भधारण की सावधानीपूर्वक निगरानी करने की आवश्यकता है।

पूर्वधारणा मूल्यांकन

- रक्ताधान की आवश्यकता
- लोह निष्कासक चिकित्सा का अनुपालन
- लोह अतिभार स्थिति
- अप्रत्यक्ष कूब्स का परीक्षण
- एचआईवी, हेपेटाइटिस बी और सी संक्रमण के लिए स्क्रीन
- लोहे के अतिभार से प्रमुख अंग क्षति का आकलन करें
- साथी के आनुवंशिक मूल्यांकन और आवश्यकता अनुसार प्रसव पूर्व भ्रूण का परीक्षण

गर्भावस्था पर प्रतिकूल प्रभाव निर्भर करता है

- एलोइम्यून एंटीबॉडी की उपस्थिति
- हृदय रोग
- गंभीर मधुमेह
- जिगर रोग
- सक्रिय हेपेटाइटिस/एचआईवी
- प्लीहा वृद्धि

प्रसव पूर्व देखभाल

- फोलिक एसिड
- अंतर विषय टीम बहु विषयक विशेषज्ञ दल
- फेरिटिन और रक्त कण का स्तर मायने रखता है एचबी 10g/डीएल बनाए रखने के लिए रक्त आधान
- प्रारंभिक अवस्था में हृदय, अंतःस्त्री तथा यकृत जाँच और प्रत्येक तिमाही में दोहराएं
- मधुमेह और हाइपोथायरायडिज्म के लिए जाँच
- भ्रूण वृद्धि और स्वास्थ्य
- गर्भावस्था में लोहनिष्कासक दवा बंद के देनी चाहिए

हाल ही में 58 थैलासीमिया मेजर गर्भवती महिलाओं की श्रृंखला में, अंतर्गर्भाशयी विकास अवरुद्धता और प्रीटर्म डिलीवरी 40% पाई गई, 15% में IGT विकसित हुआ अथवा असामान्य GTT हुई, रक्त आधान की आवश्यकता बढ़ी और बेसलाइन फेरिटिन में 60% वृद्धि हुई थी। कई जुड़वां गर्भधारण थे क्योंकि ज्यादातर महिलाओं ने गोर्नैडोट्रोपिंस का उपयोग करके ओव्यूलेशन इंडक्शन की थी।

हृदय रोग मृत्यु का महत्वपूर्ण कारण है।

प्रसव: प्रसूति संबंधी संकेतों के अनुसार प्रसव का मार्ग। छोटे कद या गर्भावस्था से संबंधित अन्य जटिलताओं के कारण सिजेरियन सेक्शन की दर अधिक है।

25th International Thalassemia Day – Fortnight Celebrations

1) NTWS started ITD fortnight celebrations with a visit to Lovely Professional University, Phagwara Punjab on Thursday 25th April 2019. The activity was organized in collaboration with Thalassemia Free India & Welfare Association. Over 300 students came to attend the



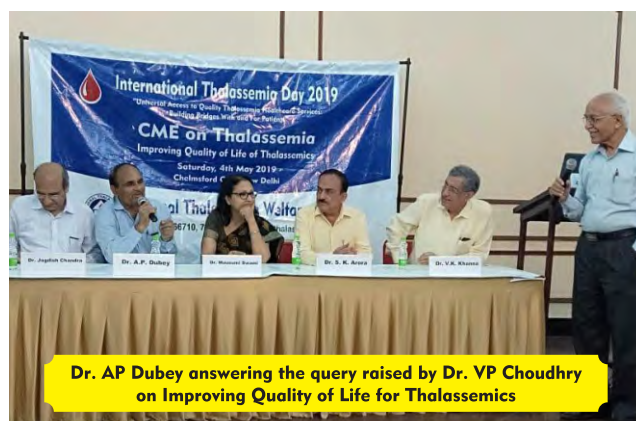
session on thalassemia and blood donation. Dr. JS Arora was invited to give a lecture on overview of thalassemia. He stressed the need of thalassemia screening at premarital stage and if missed then before/early conception. Dr. Praveen Sobti encouraged them to donate blood so that thalassemics do not have to face shortage of blood. She highlighted the need and benefits of blood donation. Mr. TS Bhatia Secretary Thalassemia Welfare Jalandhar thanked Nitish, Pooja & their team for organizing a seminar on thalassemia and regularly donating blood.



2) On Sunday 28th April'19 NTWS in association with Mahavir International Faridabad organized a free ferritin test and free hepatitis B, C screening. NTWS also supported Mahavir International in

providing free HLA typing of patient with their sibling below 10 years of age.

3) On 4th May'19 we organized a Panel Discussion Improving Quality of Life for Thalassemics at Chelmsford Club Rafi Marg New Delhi. Dr. SK Arora additional DHS and Programme Officer for thalassemia Delhi Govt. highlighted the programme and initiatives taken by Govt. of Delhi. He said Govt of Delhi has issued circular to provide transfusion services all 7 days including Sundays and holidays at all day care centres. He said we are planning to introduce thalassemia screening 10th class students and certificate to be issued with report on



back of the certificate. He also informed that free medicines and leucodepleted blood will be provided at all 13 government hospitals in Delhi (5 Delhi Govt, 3 MCD & 5 central Govt hospitals). Dr. Mausumi Swami Director State Blood Transfusion Council and HOD DDU



Hospital Blood Bank highlighted the current status of blood in Delhi. Dr. VP Choudhry, Dr Jagdish Chandra, Dr. AP Dubey & Dr VK Khanna answered the question raised by young doctors from various hospitals.

4) NTWS introduced an altogether new concept and organized a meeting of adult thalassemics with health professional, Govt. officials from ministry of health & social welfare and corporate on 5th May'19 at Constitution Club, New Delhi. This was organized in association with Youth Thalassemic Alliance (YTA). Ms Sangeeta Wadhwa welcomed

25th International Thalassemia Day – Fortnight Celebrations

the audience and conducted the programme. The event was inaugurated by the Chief Guest Mr. TD Dhariyal commissioner disability Govt. of Delhi. Mr. Dhariyal threw light on Thalassemia and RPWD Act 2016. The theme of the meeting was - Health, Wealth & Family. The focus was on treatment facilities in Delhi and other parts of India, disabilities issues, employment, marriage and family. Around 100 adult thalassemics participated, Mr. Pankaj Sethi, Mr. Devlin Roy, Ms. Pooja Gupta, Mr. Prateek Arya, Dr. Rimjhim Bakshi, & Mr. Hemant Bellani deliberated on problems faced by them and how they overcame. They also raised the issues before the authorities which still need to be addressed.



Mr. TD Dhariyal said that “Thalassemia, Sickle Cell Anaemia and haemophilia have been included in the RPWD Act 2016. Now thalassemics come under 5% reservations for higher education under disability. However they have no reservation in employment but now they cannot be refused or discriminated on health grounds. Thalassemics will be entitled to all the benefits under schemes made for disabled persons except reservations in jobs.”



Mrs. Vinita Srivastava National Senior consultant & co-ordinator Blood cell – NHM was Guest of honour for the event. Mrs Vinita Srivastava apprised the audience that National guidelines on management and prevention of Haemoglobinopathies (Thalassemia & Sickle Cell anaemia) were published in 2016, Policy draft is ready, may be notified any time after the elections. Funds have been released to

provide adequate treatment to thalassemics in each state.

The event also saw the support of corporates like Soil, Jaquar and RNA Technology & IP Attorneys who came together and talked about policies with regard to Thalassemia patients. The corporate reiterated that they are taking steps and changing policies recruiting Thalassemia patients.

Dr. JS Arora While thanking Mrs Vinita for taking initiatives to provide adequate treatment specially recently in Punjab & Karnataka, but unfortunately in most states still the condition is grim specially in Haryana, Delhi, UP & Bihar. Medicines availability is inadequate and irregular. He further said that Guidelines to grade disability was notified in Jan 2018 were not rational, Criteria for grading disability in Thalassemia & Sickle cell Anaemia have been simplified by the experts but have not been notified. He requested Mrs. Vinita to get it notified at the earliest. Dr. Arora also requested Mr. TD Dhariyal commissioner disability to direct the disability boards to issue disability certificates within stipulated time. Dr. J.S Arora shared his concerns on how Delhi was first state where all the three chelating agents were always available, but now we see only one or two chelators available. He requested Dr. SK Arora additional Director Health services and programme officer for Thalassemia to take effective steps because due to erratic supply of drugs, iron overload of patients have risen to toxic level.



Mr AN Bhattacharya, Professor & Chair, Marketing & Social Innovation- SOIL, Mr. Kanwar Shamsher Relan, Head CSR- Jaquar Foundation and Ms Rachna Bakhru, Partner - RNA Technology & IP Attorneys were present. Dr. Arora requested the companies to take special care to adjust their treatment schedule like blood transfusion dates, investigations, admissions etc. with their work schedule.

On International Thalassemia Day 8th May, 2019 we organized three activities

1) Awareness camps at DDU Hospital Hari Nagar, Guru Gobind Singh Hospital Raghbir Nagar & Dada Dev Hospital Dabri in Gynaecology OPDs. Some parents of Thalassemics and marketing staff of Star Imaging volunteered and created awareness about thalassemia.

25th International Thalassemia Day – Fortnight Celebrations



Mrs Suman Thakur and Mrs Sadhana creating awareness at Gynecology OPD Dada Dev Hospital at Dabri



Mothers of Lovish and Amrit creating awareness at Gynecology OPD DDUH Hari Nagar

2) Ms Monisha Gogoi went to SOIL and gave a lecture on thalassemia and created awareness amongst the youth.



Lovish and mother of Arushi Mishra creating awareness at Gynecology OPD Guru Gobind Singh Hospital Raghubir Nagar

3) National Thalassemia Welfare Society in association with IMA WEST TOWN organized a CME to observe 25th International Thalassemia Day on Wednesday 8th May 2019 at Star Imaging & Path Lab Tilak Nagar from 1PM onwards. Dr. Akshay Mehta Medical Director Deen Dayal Upadhyay Hospital Govt. of Delhi was Chief Guest.



Dr Dinesh Bhurani & Dr JS Arora with IMA West Town Doctors flanked by Star Imaging staff

Dr. Yukti Wadhawan a noted gynaecologist welcomed the audience. It was followed by Saraswati Vandana. Lamp Lighting was done by the chief guest and all the dignitaries.

Dr. JS Arora gave a concept note.



Dr. Dinesh Bhurani giving a talk on Approach to Anemia

Dr. Dinesh Bhurani talked about Approach to Anemia, the Chairpersons were Dr. M Mani, Dr. Sunita Lamba, Dr. Sudha Agarwal, Dr. Moonish Aggarwal. Dr. JS Arora enlighten on Prevention of Thalassemia, Dr. R Dutta, Dr. NV Kamat, Dr. Seema Sehgal chaired the session. Dr. Dinesh Bhurani once again gave a lecture on ITP, Chairpersons were Dr. K.S Chadha, Dr. Alok Bhandari, Dr. Anita Rajorhia, Dr. Shashi Lata Kabra. Last session was Question - Answers.



Dr JS Arora enlightening on Prevention of Thalassemia

Mr. Sameer Bhati director operations Star Imaging gave vote of thanks. Office bearers of IMA West Town were so encouraged that they promised to organize such more activities on Thalassemia.

25 वां अंतर्राष्ट्रीय थैलेसीमिया दिवस - पखवाड़ा समारोह

1) NTWS ने गुरुवार 25 अप्रैल 2019 को लवली प्रोफेशनल यूनिवर्सिटी, फगवाड़ा पंजाब की यात्रा के साथ ITD पखवाड़ा समारोह शुरू किया। कार्यक्रम को “थैलेसीमिया मुक्त भारत” नामक संस्था के सहयोग से आयोजित



Student of Lovely Professional University with NTWS Team, Dr Praveen Sobti and Mr. TS Bhatia

किया गया। थैलेसीमिया और रक्तदान पर आयोजित सत्र में भाग लेने के लिए 300 से अधिक छात्र आए। डॉ. जेएस अरोड़ा को थैलेसीमिया के अवलोकन पर व्याख्यान देने के लिए आमंत्रित किया गया था। उन्होंने विवाह पूर्व थैलेसीमिया स्क्रीनिंग की आवश्यकता पर बल दिया और यदि पहले चूक गए तो गर्भाधान की आरंभिक अवस्था में जांच अवश्य करवा लेनी चाहिए। डॉ. प्रवीण सोबती उन्हें रक्त दान करने के लिए प्रोत्साहित किया ताकि थैलेसीमिक्स को रक्त की कमी का सामना न करना पड़े। उन्होंने रक्तदान की आवश्यकता और लाभों पर प्रकाश डाला। श्री टीएस भाटिया सचिव थैलेसीमिया वेलफेयर जालंधर ने नितीश और पूजा को थैलेसीमिया पर सभा आयोजन करने के लिए धन्यवाद किया

2) रविवार 28 अप्रैल को NTWS ने महावीर इंटरनेशनल फरीदाबाद के सहयोग से मुफ्त फेरिटिन टेस्ट और हेपेटाइटिस बी, सी स्क्रीनिंग का आयोजन किया। NTWS ने 10 साल से कम उम्र के अपने भाई-बहनों के साथ मुफ्त HLA टाइपिंग उपलब्ध कराने में महावीर इंटरनेशनल को सहयोग दिया

3) 4 मई 19 को हमने चेम्सफोर्ड क्लब रफी मार्ग नई दिल्ली में थैलेसीमिक्स के लिए एक पैनल डिस्कशन “इंप्रूवमेंट इन कालिटी ऑफ लाइफ” का आयोजन किया। डॉ. एसके अरोड़ा अतिरिक्त डीएचएस और दिल्ली सरकार के



Dr SK Arora highlighting the steps taken by Govt. of Delhi on management and control of thalassemia

थैलेसीमिया कार्यक्रम अधिकारी ने कार्यक्रम और दिल्ली सरकार द्वारा की गई पहल पर प्रकाश डाला। उन्होंने कहा कि दिल्ली सरकार ने थैलेसीमिया

देखभाल केंद्रों में रविवार और छुट्टियों सहित सभी 7 दिनों में रक्त आधान सेवाएं प्रदान करने के लिए परिपत्र जारी किया है। उन्होंने कहा कि हम 10 वीं कक्षा के छात्रों की थैलेसीमिया जांच शुरू करने की योजना बना रहे हैं और प्रमाणपत्र के पीछे रिपोर्ट के साथ प्रमाण पत्र जारी किया जाएगा। उन्होंने यह भी बताया कि दिल्ली के सभी 13 सरकारी अस्पतालों (5 दिल्ली सरकार, 3 एमसीडी, 5 केंद्र सरकार के आधीन) में नि: शुल्क दवाइयां और लेयुकोडेप्लेटेड रक्त प्रदान किया जाएगा। डॉ. मौसमी स्वामी निदेशक राज्य रक्त आधान परिषद और एचओडी डीडीयू अस्पताल रक्त कोष ने दिल्ली में रक्त की वर्तमान स्थिति पर प्रकाश डाला। डॉ. वीपी चौधरी, डॉ. जगदीश चंद्र, डॉ. एपी दुबे और डॉ. वीके खन्ना ने विभिन्न अस्पतालों के युवा डॉक्टरों द्वारा उठाए गए प्रश्नों का जवाब दिया।

4) 5 मई 2019 को NTWS ने पूरी तरह से नई अवधारणा पेश की और वरिष्ठ चिकित्सकों, स्वास्थ्य मंत्रालय के अधिकारी तथा संगठित क्षेत्र के साथ वयस्क थैलेसीमिक्स की बैठक आयोजित की। इस सभा का आयोजन युथ थैलेसीमिक एलायंस के साथ मिल कर किया गया कुमारी संगीता ने दर्शकों का स्वागत किया और कार्यक्रम का संचालन किया। इस कार्यक्रम का उद्घाटन मुख्य



Dr JS Arora requesting Mrs Vinita Srivastava to ensure regular supply of quality medicines in adequate quantity at all centres

अतिथि श्री टीडी धारियल आयुक्त विकलांगता, दिल्ली सरकार द्वारा किया गया। श्री धारियल ने थैलेसीमिया और RPWD अधिनियम 2016 के अंतर्गत थैलेसीमिया पर प्रकाश डाला। बैठक का विषय स्वास्थ्य, उपजीविका एवं परिवार पर केंद्रित था। लगभग 100 वयस्क थैलेसीमिक्स ने भाग लिया, श्री पंकज सेठी, श्री देवलिन रॉय, सुश्री पूजा गुप्ता, श्री प्रतीक आर्य, डॉ. रिमझिम



Ms Sangeeta Wadhwa Ms Monisha Gogoi, Shobri Ghosh and Aarti Yadav after receiving memento of appreciation

बख्शी, और हेमंत बेलानी ने उनके सामने जीवन में आने वाली समस्याओं पर विचार-विमर्श किया और कहा कि वे कैसे आगे निकल गए। उन्होंने उन मुद्दों

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को भी अधिकारियों के समक्ष उठाया जिन्हें अभी भी संबोधित करने की आवश्यकता है। श्री टीडी धारियल ने कहा कि "थैलेसीमिया, सिकल सेल एनीमिया और हीमोफिलिया को आरपीडब्ल्यूडी अधिनियम 2016 में शामिल किया गया है। अब थैलेसीमिक्स विकलांगता के तहत उच्च शिक्षा के लिए 5% आरक्षण के अंतर्गत आता है। हालाँकि उन्हें रोजगार में कोई आरक्षण नहीं है, लेकिन अब उन्हें स्वास्थ्य आधार पर इनकार या भेदभाव नहीं किया जा सकता है। थैलेसीमिक्स नौकरियों में आरक्षण को छोड़कर विकलांगों के लिए बनाई गई योजनाओं के तहत सभी लाभों के हकदार होंगे।"

श्रीमती विनीता श्रीवास्तव राष्ट्रीय वरिष्ठ सलाहकार NHM इस समारोह की विशेष अतिथि थी। श्रीमती विनीता श्रीवास्तव ने दर्शकों को अवगत कराया कि हिमोग्लोबिनोपैथियों (थैलेसीमिया) के प्रबंधन और रोकथाम पर राष्ट्रीय दिशानिर्देश 2016 में प्रकाशित किया गया था, नीति का मसौदा तैयार है, चुनाव के बाद किसी भी समय अधिसूचित किया जा सकता है। प्रत्येक राज्य में थैलेसीमिक्स को पर्याप्त उपचार प्रदान करने के लिए फंड जारी किया गया है।

इस आयोजन में सोइल, जैकार और आर एन ऐ टेक्नोलॉजीज एंड आई पी एटॉर्नी जैसे कॉर्पोरेट्स की भागेदारी देखी गयी। कॉर्पोरेट ने दोहराया कि वे इस दिशा में कदम उठा रहे हैं और थैलेसीमिया के मरीजों को भर्ती कर रहे हैं।

डॉ जेएस अरोड़ा ने श्रीमती विनीता को पर्याप्त उपचार प्रदान करने के लिए पहल करने के लिए धन्यवाद दिया विशेष रूप से हाल ही में पंजाब और कर्नाटक में, लेकिन दुर्भाग्य से अधिकांश राज्यों में अभी भी हालत विशेष रूप



Dr JS Arora giving memento to Ms Rachna Narula



Mr. Shamsher Singh Relan highlighting association of Jaquar with NTWS

से हरियाणा में गंभीर है, दिल्ली, यूपी और बिहार में दवाओं की उपलब्धता अपर्याप्त और अनियमित है। उन्होंने आगे कहा कि जनवरी 2018 में विकलांगता की आंकलन के दिशा-निर्देश अधिसूचित किए गए थे, थैलेसीमिया में विकलांगता आंकलन के लिए मानदंड तर्कसंगत नहीं थे उन्होंने श्रीमती विनीता से इसे जल्द से जल्द अधिसूचित करने का अनुरोध किया। डॉ अरोड़ा ने श्री टीडी धारियाल को विकलांगता समिति को निर्धारित समय के भीतर विकलांगता प्रमाण-पत्र जारी करने के लिए निर्देश देने के लिए आग्रह किया। डॉ जे.एस. अरोड़ा ने इस बात पर अपनी चिंताओं को साझा किया कि दिल्ली पहला राज्य था जहां सभी तीन chelating एजेंट हमेशा उपलब्ध थे, लेकिन अब हम केवल एक या दो chelators उपलब्ध देखते हैं। उन्होंने डॉ एस.के. अरोड़ा अतिरिक्त निदेशक स्वास्थ्य सेवाएं और थैलेसीमिया के लिए कार्यक्रम अधिकारी को प्रभावी कदम उठाने के लिए कहा क्योंकि दवाओं की अनियमित

आपूर्ति के कारण, रोगियों में लोहे का अधिभार विषाक्त स्तर तक बढ़ गया है।



Mr. Anil Thakral and Ms Tanu Thakral receiving couple lucky draw from Mr. Relan



Mr. Mohit Sharma and Ms Pooja Chawla Sharma receiving couple lucky draw from Ms Rachna Narula

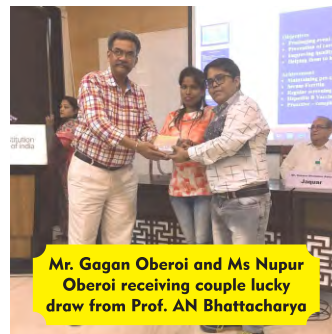
श्री एएन भट्टाचार्य, प्रोफेसर और अध्यक्ष, विपणन और सामाजिक नवाचार-एसओआईएल, श्री कंवर शमशेर रिलन, प्रमुख सीएसआर- जैकार फाउंडेशन और सुश्री रचना बखरू, पार्टनर - आरएनए प्रौद्योगिकी एवं आईपी अटार्नी उपस्थित थे। डॉ. अरोड़ा ने कंपनियों से अनुरोध किया कि वे थैलेसीमिक्स के



Dr Rimjhim Bakshi receiving token of appreciation



Ms Pooja Gupta receiving token of appreciation



Mr. Gagan Oberoi and Ms Nupur Oberoi receiving couple lucky draw from Prof. AN Bhattacharya



Mr. Pankaj Sethi receiving token of appreciation

उपचार के कार्यक्रम जैसे रक्त आधान की तारीखों, जांच, प्रवेश आदि को अपने कार्य अनुसूची के साथ समायोजित करने के लिए विशेष ध्यान रखें।

Dr JS Arora, Ms Monisha Gogoi & Ms Aarti Yadav from NTWS participated in a workshop CSR of People with Disability at Dwarka organized by Sarthak.



4th WOMEN ASTITVA SAMMAN 2019



NTWS Team during 4th Women Astitva Saman Award function at PHD Chamber of Commerce

National Thalassemia Welfare Society was honoured by 4th WOMEN ASTITVA SAMMAN 2019 programme on February 15, 2019 at the PHD House, New Delhi. By PHD Women and Child Development Committee. The “SAMMAN” is given to the organizations which work for the growth of women within the organization by “Training interventions, women empowerment & gender sensitive workplace”

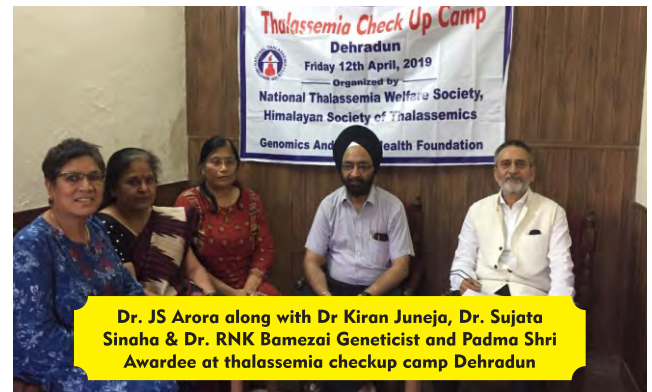
Dr JS Arora General Secretary National Thalassemia Welfare Society was honored with the “SAMMAN” on behalf of NTWS.



Thalassemic Children Welfare Society Jalandhar has arranged a free Medical check up & distribution of free medicines camp for thalassemic patients in Thalassemia ward civil hospital Jalandhar, on 31st'

march 2019. (Sunday) at 10 a.m. Dr. J.S.Arora (NTWS New Delhi) & his team examined all the patients & their lab tests (being got done by TCWS) and prescribed required medicines to them. S.Inderjeet Singh Ghattaur, Daljeet Singh Sian & Biba Jaswant Kaur ji of U.K along with Sh. S.S. Khattar (managing director Help Thalassemics) distributed the prescribed medicines free to the patients report by Er. T.S. Bhatia Gen. Secy. TCWS Jalandhar.

Dehradun



Dr. JS Arora visited Dehradun and held a thalassemia checkup camp over there on 11th & 12th April 2019. He along with Mr. Puneet Kaura visited Shri Mahant Indires Hospital Dehradun. Dr. Utkarsh HoD Pediatrics agreed to start a thalassemia unit in is department.



CME on Thalassemia organized at Swami Dayanand Hospital (SDH), Shahdara on 5-04-2019 Dr Sonam Upadhaya give a talk on Transfusion Therapy, Dr. Nandlal Chaudhary spoke on

Complication of Transfusion Therapy, Dr. Arora enlightened about Iron Overload and Chelation, Dr. Richa Maurya stress the need of Prevention of Thalassemia and Dr. VP Choudhry gave a lecture on ITP.

International Thalassaemia Day 2019, Hindu Rao Hospital

Thalassaemia Day Care Center, Hindu Rao Hospital

Thalassaemia Day Care Center was established 15 years back on 8th May 2004. Unit celebrates 15 years of providing quality services to Thalassaemia Major Patients. The unit has been organizing different activities each year. This year on 4th May to celebrate International Thalassaemia Day a cultural programme was organized, in which Thalassaemia Major Patients of the center performed.

Children took active part in doing decoration making Rangoli etc. The paintings made by children were very attractive and displayed outside the Hall.

Dr Alka Mathur, in charge Thalassaemia Day Care Center elaborated the theme of the International Thalassaemia Day 2019 and how the center is trying to bridge the facilities for the patients.



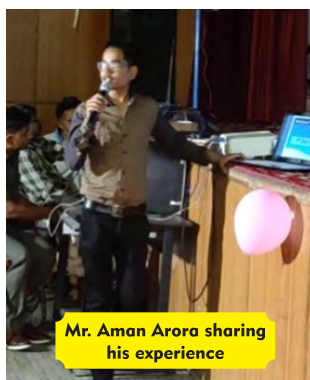
Thalassaemia patient and staff of thalassaemia day care centre at Hindu Rao Hospital

For all the patients above 10 years T2 * MRI was done free of cost from AIIMS by coordinating with Hematology and Radiology department of AIIMS. It has been coordinated to get HCV RNA done from NCDC and in future free medicines will also be provided. Blood Bank in-charge has coordinated with Indian Red Cross Society for getting blood from Red Cross Blood Bank for patients with Auto and Allo antibodies and testing for the needed patients.

Dr Alka gave report of the last 15 years how the number of 15 in 2004 has increased to 82 since last year. Due to shortage of beds it was decided in a meeting at DHA office that no new patients will be registered till beds are increased or there is a vacancy due to any reason. Till that time either they will be given transfusions in the emergency ward or efforts will be made to get that patient registered at another center.

Thalassaemia Major Mr. Aman Arora, who is taking treatment from HRH Thalassaemia Day Care center, shared his journey with thalassaemia Major at Hindu Rao Hospital.

Master Akhilesh 14-year-old raised the question of difficulty of arranging blood donor. On behalf of Incharge Blood bank it was declared unless there is acute shortage no replacement will be asked from Thalassaemia Major Patients.



Mr. Aman Arora sharing his experience

The cultural programme was by patients of thalassaemia major of the center. They showed their other skills also like painting and decorated the hall with rangoli etc .

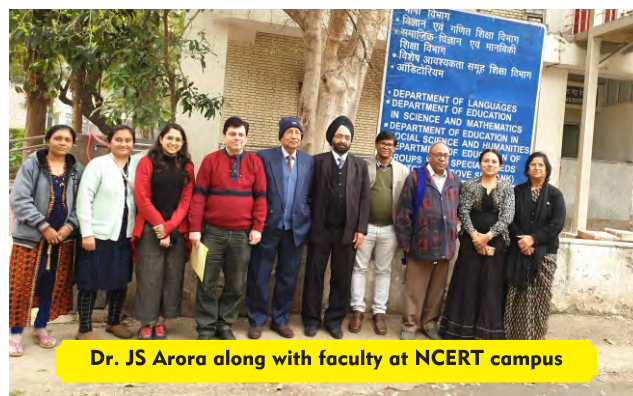
Mrs Kiran mother of two Thalassaemia Major shared her journey and how Thalassaemia Day Care, Hindu Rao Hospital has made it easier.

Dr. Raju, HOD Paediatrics and Additional MS assured about the efforts for availability of Medicines and filters. Additional MS. Dr.

Vibha Verma also requested need for more involvement of medicine department of caring of the adult patients Dr. Raju also stressed the need of separate ward for Adult children.

NCERT Initiative on newer disabilities

The Rights of Persons with Disabilities Act, 2016 includes haemophilia, thalassemia, sickle cell disease. Children affected with these medical conditions are facing difficulties in their day to day life as well as in receiving quality education. This DEGSN (Department of Education of Groups with Special Needs) has under taken a research study entitled "Education of Children with Disabilities due to Chronic Health Impairments: Case studies" for the year 2018-2020.



Dr. JS Arora along with faculty at NCERT campus

The objectives of this study was to explore the nature and severity of CHI causing disabilities in children, to identify the difficulties in learning among these children, to study the existing education interventions for these children with reference to their clinico-therapeutic profile and to analyse the efficacy of existing educational intervention programmes on learning outcomes. A pilot study was conducted with children having thalassemia at the NTWS Centre Tilak Nagar, New Delhi on Sept., 9th, 2018.

In this regard, the draft research tools were prepared. The department organized a three day workshops for finalization of the developed tools from 13th and 15th February, 2019 at DEGSN-Centre, NCERT campus, New Delhi. Dr. VP Choudhry and Dr. JS Arora were invited to the Department of Education of Groups with Special Needs (DEGSN) at Sri Aurobindo Marg, New Delhi-110016 to give their expert opinion

NCPEDP Meeting, 2019

National Centre for Promotion of Employment for Disabled People (NCPEDP) an umbrella organization of cross disabilities organized meeting of the national consultation on the Convention on the Rights of Persons with Disabilities (CRPD) report on 11th & 12th January '2019 at USI, New Delhi.

Indian Government had submitted the Country Report to the UNCRPD Committee. NCPEDP had worked on a parallel report in the previous

years and this year again to have a final consultation on the same, activists from various disability groups were invited to contribute to this paradigm change in the disability movement in India.



Dr. JS Arora and Ms Monisha Gogoi attended this meeting to share their views from NTWS.

WHO expert consultation to enhance patient and family engagement for the provision of safer health care 5th & 6th February 2019, Lisbon, Portugal.



Dr. JS Arora along with Sir Liam Donaldson World Health Organization's envoy for patient safety, Chair in Public Health at the London School of Hygiene and Tropical Medicine, Dr. Neelam Dhingra a Coordinator for the Patient Safety and Quality Improvement Unit, in the Service Delivery and Safety Department at the World Health Organization, Mr. Kawal Deep Singh Sehmi CEO of IAPO and other international delegates at Patient for Patient Safety advisory group meeting at Portugal.

Dr. JS Arora general secretary National Thalassemia Welfare Society was invited to the meeting “Strengthening the WHO Patients for Patient Safety programme to enhance patient and family engagement for the provision of safer health care” as member advisory group Patients for Patient Safety on 5th & 6th February 2019 at Lisbon, Portugal.

The agenda was focused on Creating a global vision, strategic directions and priority. interventions for strengthening WHO PFPS programme, including training and capacity building and Taking Patients for Patient Safety programme forward.

Thalassemia awareness session at school



A special assembly was organised in Kamal Model School Mohan Garden on 10th May'19 and Dr. JS Arora was invited to sensitize the senior class students during assembly. Over 500 students were present during the assembly, though the programme was scheduled at short notice students prepared a skit on thalassemia and played on the stage. Dr. JS Arora informed that thalassemia major is genetic disorder, treatment is very costly but preventable. He apprised audience about the latest development in the prevention and cure of thalassemia. He interacted with students and staff members and gave detailed answer in reply to their doubts. Dr. JS Arora appreciated the sincere effort of Mrs Vandana Tendon principal and Mrs Pushpa Jindal, academic Advisor for taking initiative for such a noble cause.

Thalassemia Awareness



Shri Ram Global School, Delhi-West also held a thalassemia awareness programme with the students during assembly session on Friday, 24th May, 2019 in the school premises. Dr. JS Arora was invited to sensitize the students and teachers on Thalassemia. Ms. Aarti Yadav also accompanied to the event.



Thalassemia awareness and screening camp organized by IRCS Ahemdabad



ITD 2019, Samaroh Akola, Maharashtra



NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

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

www.thalassemiaindia.org, E-mail : ntws2019@gmail.com

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NTWS Thalassemia Centre

Free Thalassemia Clinic, 2nd Sunday every month

Registration time : 9am to 12 noon

Address

NTWS Thalassemia Centre,
2nd 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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National Thalassemia Welfare Society

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

Life Member	Indian	INR	500
	NRI/Foreigner	USD	100
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NTWS Blood Donation Camps, January to May, 2019



**Haryana Roadways Association Gurgaon,
Blood donation Camp**



**Blood donation Camp organised
at Soil, Gurgaon**



**Blood donation Camp organised
at Tata Capital, Jhandewalan**



**DGM & Senior Managers of OBC Gurgaon
donating blood**



**Blood donation Camp organised
at Axis Bank, Noida**



**Blood donation Camp organised
at HSBC, Gurgaon**



**Blood donation Camp organised
at DLF Promenade, Vasant Kunj**



**Blood donation Camp organised
at WNS Global Services, Noida**



**Dr. Monica, Monisha Gogoi & the Students
of IITM Janakpuri after donating blood**



**Blood donation Camp organised
at Bechtel India, Gurgaon**



**Blood donation Camp organised
at Tata Capital, Lajpat Nagar**



**During Blood donation Camp organised
at DLF Promenade, Vasant Kunj**