DR VINKY RUGHWANI - A SOCIAL CRUSADER STRIVING FOR THALASSEMIA AND SICKLE CELL AFFECTED

Pre-amble:

Sickle cell disease and thalassemia are **genetic disorders caused by errors in the genes for hemoglobin**, a substance composed of a protein ("globin") plus an iron molecule ("heme") that is responsible for carrying oxygen within the red blood cell.

Sickle beta + thalassemia is **a disease that causes a mild form of sickle cell anemia**. This causes the body's hemoglobin, or red blood cells, to take on a sickle shape and not flow through the blood vessels as smoothly. This can cause a number of complications.

SICKLE CELL DISEASE IN INDIA: A PERSPECTIVE

Sickle cell disease is an inherited blood condition which is most common among people of African, Arabian and Indian origin. In disease of African origin, research has led to models of care which prevent serious complications, improve the quality of life, and increase survival. In India, the disease is largely undocumented. Thus, there is an urgent need to document the features of Indian disease so that locally appropriate models of care may be evolved.

The sickle cell mutation affects the beta chain of adult haemoglobin which changes the behaviour of sickle cell haemoglobin. Possession of a single gene results in the generally harmless sickle cell trait (AS genotype) but inheritance of the gene from both parents results in homozygous sickle cell (SS) disease which is often a severe condition destroying red blood cells rapidly and blocking flow in blood vessels with painful and often serious complications. The HbS mutation has occurred on at least three occasions in Africa, named after the areas where these were first described, Benin, Senegal and Bantu (Central African Republic) and referred to as the beta globin haplotypes. A separate and fourth occurrence of the mutation was seen around the Arabian Gulf and India and designated the Arab-Indian or Asian haplotype.

SICKLE CELL GENE IN INDIA

First described in the Nilgiri Hills of northern Tamil Nadu in 1952, the sickle cell gene is now known to be widespread among people of the Deccan plateau of central India with a smaller focus in the north of Kerala and Tamil Nadu. Extensive studies performed by the Anthropological Survey of India have documented the distribution and frequency of the sickle cell trait which reaches levels as high as 35 per cent in some communities.

India has the largest number of children with Thalassemia major in the world – about 1 to 1.5 lakhs and almost 42 million carriers of ß (beta) thalassemia trait. About 10,000-15,000 babies with thalassemia major are born every year.

CORPORATE SOCIAL FOCUS – A NATIONAL CSR MAGAZINE Introduces **Dr Vinky Rughwani,** Pediatrician & President of **Thalassemia and Sickle Cell Society of India,** also running the **Rughwani Child Care Centre & Hospital** in Nagpur, Maharashtra.

Dr Vinky Rughwani has spearheaded the Mission since last 22 years championing for this cause thru his untiring efforts to the services of these poor children.

THALASSEMIA MINOR - A DISABILITY IN INDIA:

The RPWD Act 2016 has recognized persons with blood disorders (Thalassemia, Hemophilia and Sickle Cell Disease) as 'persons with disabilities' under the Act.

Those with 40% and above disability will be given a Disability Certificate.

DR. VINKY RUGHWANI, A SOCIAL CRUSADER WITH BLOOD IN HIS MIND

Dr. Vinky Rughwani did his MBBS from Government Medical College, Nagpur in 1992. He chose Pediatrics as his subject for specialization. As he was pursuing his post graduation he witnessed patients regularly coming for blood transfusion as they suffered from Thalassemia and Sickle Cell disease. The number was alarming. Everything was there, the doctors to treat them, medical advice from experts and medicines. But these were not adequate to resolve their problems and sufferings. All of a sudden his life started resolving around these patients. He developed special interest in these Thalassemia and Sickle Cell disease. He became child specialist in 1995. After his post graduation he started his hospital Rughwani Child Care Centre and Hospital in Nagpur. During his private practice he felt that there was lack of attention and work to be done for these patients. It was seems that these patients of Thalassemia and Sickle Cell were somehow neglected. There was a need of attention from medical fraternity so that something significant could be done for these.

Nagpur is situated in the eastern part of Vidarbha where the number of patients suffering from Thalassemia and Sickle Cell disease were in large numbers. When he came across such patients day in & day out he was devastated. It was then that he could realize why destiny compelled him to work amongst children. This was his calling. He was born for a mission. He says the misery and agony that the patient and his family go through their lives cannot be expressed in words. This disease is most common in under privileged caste and community of the society. The expenses required for the management of these diseases is not cup of tea for these patients and their families. Arrangement of blood, medicines and doing costly investigations is not possible for them. Witnessing all this and much more, it compelled him to buckle up his shoes and roll up his sleeves. He set up a separate unit in his hospital called Thalassemia and Sickle Cell Centre to render free services to these patients. Services included free blood transfusion, free medicines, free consultation etc. Very soon this work of his got attention by the patients wide spread as they say this was long awaited by them. He was being called their crusader and godsend.

He has got many awards in his name including special award for his medico social work by Government of Maharashtra. He got Times Award for his excellent work in Thalassemia and Sickle Cell disease. He received Covid Warrior Award at the hands of Hon. Bhagat Singh Koshyari, Governor of Maharashtra. He got Professional Excellence Award for his work by Association of Medical Faculties.

"We all are born with a mission. But unfortunately many keep finding that mission their entire life. Fortunate are those who find it well before going to the grave. We all are sent here for a reason and that we all have significance in this world. We all are blessed with unique gifts. The expressions of our gifts contribute to a cause greater than ourselves. My mission is to irradiate the diseases Thalassemia and Sickle Cell disease from the country with the support and assistance of you all. I dare to dream of a world where no life is lost due to these diseases. My Moto is to spread awareness so that no family witnesses the birth of their child with any of these diseases."

Says **DR. VINKY RUGHWANI**
Paediatrician and President,
Thalassemia and Sickle Cell Society of India.

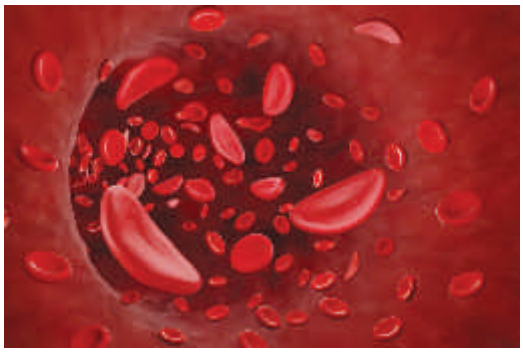
Dr. Vinky Rughwani with Thalassemia Patient

Dr. Vinky Rughwani receiving Zee Health Care Award

Dr. Vinky Rughwani got Prestigious Zee Health Award in a glittering ceremony held at Hotel Hyatt Regency, New Delhi. Zee Digital Media and India.com organized this event to felicitate individuals and organizations for doing excellent work in the field of Health in our country. Union Minister of State for Health and Family Welfare Dr. Bharti Pawar was the Chief Guest on that occasion. Dr. Vinky Rughwani got this award for his Momentous work in the field of Thalassemia and Sickle Cell diseases. He is working for prevention and welfare of patients suffering from these diseases in last 22 years.

WHAT IS THALASSEMIA MAJOR DISEASE:

Thalassemia major is a serious and genetic disease. A child or patient suffering from this disease needs to give blood for the rest of his life. Once a month in the beginning and gradually as the age increases, the need of blood also increases. Older children and adult patients also have to give four units of blood in a month. Apart from blood, they also have to go through many expensive tests. Expensive medicines also have to be taken. There is only one permanent treatment for this disease that is bone marrow transplantation which is very expensive. It costs about 15 lakh rupees and at the same time there is a risk in it. We can imagine what will be the mental and financial condition of the members of the family in which the child of Thalassemia Major will be there. Therefore it is necessary that such children and patients should not be born in our home, in the society and in the country. And this is possible because Thalassemia Major is 100% preventable.



PREVENTION OF THALASSEMIA MAJOR:

A child with Thalassemia Major is born only if both of his parents are Thalassemia Minor. Thalassemia Minor is a completely normal person, but when a Thalassemia Minor man marries a Thalassemia Minor woman, then their child get a fatal disease like Thalassemia Major, one who has to bear suffering for the rest of his life. That is why it is necessary that every boy and girl must get Thalassemia Minor tested before marriage so that the child of Thalassemia Major is not born.

What is Sickle Cell disease:

Sickle Cell is a genetic and dreaded disease. This genetic disease is more common in SC and ST community. Usually this disease is found in almost all communities to some extent. People suffering from this disease could be seen more commonly in certain parts of India. A patient suffering from Sickle Cell disease gets pain in limbs, abdomen and all over the body off and on. For this severe body ache these patients many times have to be admitted in the hospital. As their hemoglobin level is low, the patients have to undergo blood transfusion sometimes. Hydroxy urea, Folic Acid and other medicines have to be taken by these patients throughout their lives. They even have to often go through expensive blood tests, sonography etc. With the advancement of age, the patients suffer from complications of the disease. Avascular Necrosis of Head is one of the most common complication which poses problem in movement of these patients. Replacement of joints is the only remedy for this complication. The permanent cure for sickle cell disease is Bone Marrow Transplantation which costs approximately 14 to 15 lakhs. Getting the HLA match for Bone Marrow Transplantation is also difficult. Moreover the whole process is too risky as it poses a threat to life.

PREVENTION OF SICKLE CELL DISEASE :

Mentioning about prevention this disease can be totally controlled if proper approach is adopted. This disease is fully preventable disease. The child of Sickle Cell disease (SS Pattern) is born only when both of his parents have Sickle Cell Trait. Persons having Sickle Cell Trait is absolutely normal and is asymptomatic. When a boy having sickle cell trait marries with a girl having sickle cell trait there are chances of getting birth of child having sickle cell disease. Hence it is necessary to undergo test of Sickle Cell Trait for the boys and girls before marriage. This practice could go a long way in checking this disease.

Hence instead of matching horoscope it is more important to match blood for Thalassemia and Sickle Cell disease for prevention of these dreaded diseases.

INFORMATION ABOUT THALASSEMIA AND SICKLE CELL SOCIETY OF INDIA :

Thalassemia and Sickle Cell Society of India is working for welfare of Sickle Cell and Thalassemia patients and prevention of this illness in the Country especially in the Central part of India since more than 22 years bringing huge social, health impact for thousands of families. Dr. Vinky Rughwani is the Founder President of this organization. People belonging to medical fraternity and social workers are members of the society.

Organization established a Centre for Sickle Cell and Thalassemia children with all modern technologies at Nagpur (Maharashtra). Children suffering from Sickle Cell and Thalassemia Major Disease are given free medical services, free consultation, free medicines (to needy and poor patients) and free blood transfusion facility. Patients from state of Maharashtra, Madhya Pradesh, Chhattisgarh and many other states take use of the available facilities at the centre. It has changed complete scenario and help for Sickle Cell and Thalassemia patients in this region.

Thalassemia and Sickle Cell Society of India renders a great service to children who need regular blood transfusion by organizing regular blood donation camps and offering free transfusion to thousands of Sickle Cell and Thalassemia Major Disease children at his Centre.

During Covid-19 pandemic Sickle Cell and Thalassemia patients were not getting blood due to shortage of voluntary blood donation camps. Due to efforts and struggle of Thalassemia and Sickle Cell Society of India various small blood donation camps were organized in central part of India during pandemic and which help these patients waiting for Blood Transfusions which was highly appreciated by State Blood Transfusion Council, Government of Maharashtra by issuing a appreciation letter in the year 2021.

Due to enormous efforts of organization Sickle Cell and Thalassemia disease were included in the list of Persons with Disability. The organization pursued the matter with Central Government (through Minister of Social Justice and Empowerment), (through Chief Minister of Maharashtra). Due to his proactive initiation and years of determination Sickle Cell and Thalassemia patients will get reservation of 5% in education.

As financial and social contribution organization worked and raised funds from Prime Minister Relief Fund, Chief Minister Relief Fund and other donors and gave life to more than 50 children suffering from Thalassemia Major disease and they have undergone Bone Marrow Transplantation which costs lakhs of rupees and was beyond the capacity and affordability of these children. This has impacted and gave hope to many patients of these diseases.

Organization has also been instrumental in making medicine free of cost needed for the treatment of Sickle Cell and Thalassemia disease for under privilege, BPL, Tribal and needy patients. Organization also created awareness about these diseases amongst the general mass to check the spread of this disease in the regions like Maharashtra, Madhya Pradesh, Chhattisgarh and other parts of Country.

Organization has worked contributed with different social activist groups, government institutions, hundreds of NGOs and doctors and organized thousands of free Thalassemia Minor and Sickle Cell detection camps which has benefited lakhs of families. Organization reached hundreds of Schools, Colleges, Communities and through Medical Camps has succeeded in free testing of more than 55000 boys and girls and helped in prevention of these diseases.

In many parts of the country, organization is instrumental in organizing People's Meet; Public Forum, Seminars, Workshops addressed by specialist in the field of Sickle Cell and Thalassemia disease. This helped more than 5 Lakh population. As a commitment to Women and Child Welfare organized free check up camps for pregnant women for Sickle Cell Trait and Thalassemia Minor and save hundreds of families who could prevent birth of Thalassemia Major and Sickle Cell disease child.

For lively hood of patient and their families, various skill development programmes and job assistance programmes are organized at the Thalassemia and Sickle Cell Society of India. As a commitment to society organization offered free education, books material to more than 500 Patients of Sickle Cell Trait and Thalassemia Major Disease.

Thalassemia and Sickle Cell Society thanks and salutes each and every individual who came forward to donate blood in this sensitive period of COVID-19 pandemic.

THE FACILITIES GIVEN TO THALASSEMIA AND SICKLE CELL PATIENTS:

- Free consultation to all.
- Free Blood Transfusion to all.
- Providing disposables (Syringes, BT Set, Distill Water etc.) free of cost.
- Free medicines to poor patients.
- Blood and other investigations for all at Pathology Laboratory (Magnum Lab.)
- Free consultation by Endocynologist, Orthopedician, Psychologist, Hematologist whenever required and after any complications.
- Facility of admitting these patients whenever they require hospitalization.
- Those who require Bone Marrow Transplantation are given guidance and help.
- Free Thalassemia Minor Test and Sickle Cell Trait Test on specific days.
- Couple who are both minors are advised CVS Testing.
- Education Programme for patients and parents about the disease.
- Training of Health Care Workers who are involved in Management of Thalassemia and Sickle Cell disease.

Initially there were only 50 registered patients with the society. All the expenses of the society were born by Dr. Rughwani. His friends and some social organizations applauded his work and came forward with monetary help, which bought a sign of relief. But this was short lived. Today there are 1000 Thalassemia and Sickle Cell patients registered with the society. Since then till today, everything is on a rise, number of patients, requirement of blood and medicines, man power, upgradation of technique to assist treatment. Patients trust, faith, belief and expectations everything has risen multifolds and now it is getting difficult for the society to carry on improvised work with such high figures of everything. But at the same time putting any foot back is not in the option's list. A few decades back the world was fighting hard to push back polio out of the globe. This was a mission that was taken up by all segments of the society, the government, the administration, rotary club, social organizations, NGO's and individuals. A dream seen then came to be true, although after decades of hard work. Similarly to see the country free from Thalassemia and Sickle Cell disease, a lot is to be done and a lot is required for this to be done. Once again it's time for government, government organizations, NGO's, big corporate houses, private organizations, registered clubs, institutions and individuals to come together and contribute in order to make this dream true. We need to work with the same motto and rhythm, enthuse and vision as we all have worked decades back for polio. We all need to join hands and stand tall together as a wall in front of each obstacle that comes our way in prevention and eradicating these diseases from the world. We have done it before. Let's do it again, for the sake of humanity, for the sake of each suffering person, for the sake of each child who is born with these diseases.

GOVERNMENT is already supporting the same through it timely intervention and various announcements on policy matters, It is now for the CORPORATE, PSU, Private Ltd companies under the CSR ambit to pitch in more support to this deadly disease.

The Below coverage is to emphasis the point that every organization, be it the government, society, association and the responsible PSU is doing their bit to support the work already being done. It is high time, that more corporate, private companies under CSR ambit, PSU thru their CSR funds, should start pitching in to do their part of the bit, so that a collective effort can definitely add to the ongoing support system and play a major role in containing the disease to a certain extent.

Thalassemia and Sickle Cell Society of India is registered under section 12A vide registration no. CIT-I/12A/T-16/2012-13 and also **under section 80G vide registration no. CIT-I/Tech./80G/T-16/2014-15. Hence donor gets Income Tax benefit of deduction of 50% of amount contributed as a donation.**

At present our society is getting some help from organizations like Sankalp Foundation and Central Mine Planning & Design Institute Limited. If one could be of any help to the people who are struggling hard to survive, this gives internal peace and contentment to the soul. Looking forward for help.

INFORMATION ABOUT THALASSEMIA AND SICKLE CELL CENTRE :

Thalassemia and Sickle Cell Centre at Nagpur is run by Thalassemia and Sickle Cell Society of India. It was established in 2010. Initially there were less than 100 patients of Thalassemia and Sickle Cell disease. Slowly and gradually the number of these children increased at present there are 776 registered patients of Thalassemia Major and 352 of registered patients of Sickle Cell disease in this centre. These patients are regularly being treated at the centre and get admitted whenever they require. They are given free blood transfusions at the centre. Also the disposables required for transfusion for patients giving free of cost. Few of the patients are getting free medicines like iron chelators at the centre. These patients frequently need blood investigations which are provided free of cost to few poor needy patients.

FOLLOWING IS THE ARCHIVAL NEWS TO PROVE THE POINT OF SERIOUSNESS THE GOVERNMENT AND VARIOUS RESPONSIBLE AFFILIATES SUPPORT RECEIVED FOR THE SAID DISEASE.

Dr. Vinky Rughwani felicitating Hon'ble Shri. Mohanji Bhagwat

Hon'ble Shri. Mohanji Bhagwat addressing during the Genetic Blood Match App Inaugural Programme

GENETIC DIGITAL BLOOD MATCH APP :

Thalassemia and Sickle Cell are serious diseases. Patients suffering from Thalassemia need to give blood every 15 to 20 days and have to take expensive medicines for life. Patients suffering from Sickle Cell disease have to be hospitalized many times due to pain in the extremities and body and sometimes also need to give blood. These diseases are genetic diseases that are passed from parents to children. That is why before marriage every boy and girl should make sure that both husband and wife do not have Thalassemia Trait or Sickle Cell Trait. **A genetic digital blood match app has been prepared by Thalassemia and Sickle Cell Society of India** in which after feeding its report of Sickle Cell and Thalassemia, it will get detailed information about its Thalassemia and Sickle Cell status. He will also get information about what problems he may face in the coming time. Along with this, information will also be given about which spouse he has to marry and whom he does not want to do. Through this app it can be known that your future child will not be suffering from serious diseases of Thalassemia and Sickle Cell disease. There are more than 5 Crore people who are Thalassemia and Sickle Cell Trait in our country. This app can be used by all those people along with general population. Through public awareness and by this app, we can prevent birth of Thalassemia Major and Sickle Cell Disease child. Our goal is to make India Thalassemia and Sickle Cell free in the coming years. The inauguration was done at the hands of Sarsanghchalak Hon'ble Shri Mohan Ji Bhagwat.

Hon'ble Shri. Mohanji Bhagwat inaugurating Digital Blood Match App Programme

In October 2020, the then, Union Minister Dr. Harsh Vardhan launches second phase of "Thalassemia Bal Sewa Yojna" for underprivileged Thalassemic patients

Dr Harsh Vardhan, Union Minister for Health and Family Welfare launched the second phase of "Thalassemia Bal Sewa Yojna" for the underprivileged Thalassemic patients, virtually from Nirman Bhawan.on October 14, 2020.

Launched in 2017, this scheme is a Coal India CSR funded Hematopoietic Stem Cell Transplantation (HSCT) program that aims to provide a one-time cure opportunity for Haemoglobinopathies like Thalassaemia and Sickle Cell Disease for patients who have a matched family donor. The CSR initiative was targeted to provide financial assistance to a total of 200 patients by providing a package cost not exceeding Rs 10 Lakh per HSCT.

On the occasion, the union minister congratulated the doctors of SGPGI Lucknow, PGI Chandigarh, AIIMS Delhi, CMC Vellore, Tata Medical centre, Kolkata and Rajeev Gandhi Cancer Institute, Delhi for the successful transplantation of 135 children without charging any physician fee.

Expressing gratitude to Coal India and their CSR team for providing such opportunity to the BPL patients suffering from haematological disorders and extending the support for another two years from 2020, Harsh Vardhan mentioned the issue of high Out-of-Pocket-Expenditure on health services in India, "People go bankrupt selling ancestral land and the last property paying for their treatment.

Rajesh Bhushan, the then Union Health Secretary, Vandana Gurnani, AS&MD (NHM), Pramod Agarwal, Chairman and Managing Director, Coal India and other senior officials of the Health Ministry and Coal India were present on the occasion.

From the medical community, Dr. Vikram Mathews, HOD Hematology, CMC Vellore, Dr. Soniya Nityanand, HOD Hematology, SGPGI Lucknow, Dr. Dinesh Burrani, HOD Hematology, RGCI, Dr. Pankaj Malhotra, HOD Hematology, PGI Chandigarh, Dr. Manoranjan Mahapatra, HOD Hematology, AIIMS New Delhi, Dr. Mammen Chandy, HOD Hematology, Tata Medical Centre, Kolkata, Dr. Sunil Bhatt, HOD Hematology pediatric, Narayan Hrudayalaya, Bangalore, Dr. Joseph John, HOD Hematology, CMC Ludhiana and many children affected by Thalassemia along with their parents joined the programme virtually.

Dr. Harsh Vardhan recollects "Tears of Gratitude" while documenting Beneficiaries of Prime Minister's 'Ayushman Bharat-Pradhan Mantri Jan Aarogya Yojana' scheme that similarly reduces Financial Burden of Major Health Ailments

Approval of HSCT project for the cure of Thalassaemia patients by the Govt. of India

Coal India Ltd. under their CSR activity in coordination with the Ministry of Health and Family Welfare, Govt. of India has approved an HSCT project for the cure of thalassemia patients. They would like to help 200 patients in a year. Thalassemics India has been given an opportunity to coordinate this project as per their role defined by MoHFW, Govt. of India.

As per the approved project, a financial support of Rs. 10 lacs (USD 15625.00) per BMT will be provided to the patient.

The four hospitals recommended for BMT are:

1. CMC, Vellore
2. Tata Medical Centre,Kolkata
3. AIIMS, Delhi
4. Rajiv Gandhi Cancer Institute & Research Centre, Delhi

Hyderabad's Thalassemia society clocks 2 lakh blood donations in Sep 2022

Thalassemia and Sickle Cell Society thanks each voluntary donor and urges more citizens to come forward to eradicate the blood disorder. Thalassemia and Sickle Cell Society (TSCS), Hyderabad, has hit a milestone by registering 2 lakh blood units from donors.

Thalassemia is a genetic, incurable but preventable blood disorder, and TSCS is the only organisation in the world serving more than 3,200 patients under one roof, said president Chandrakant Agarwal.

Besides blood transfusion, doctors thoroughly examine the patients and offer all possible help with counselling. Even the Bone Marrow Transplant, which is expensive but the only treatment for Thalassemia, is being taken up for free with the help from donors under CSR activities and the support of Telangana government through Aarogyasri health scheme.

Regular HbA2 is being done in the most neglected areas around Hyderabad, Khammam and Mahbubnagar, and the society has been requesting the government to make the testing mandatory for all pregnant women by issuing an order so that both public and private practitioners can be instructed to do this test.

TSCS thanked each voluntary donor and urged more citizens to come forward to eradicate the blood disorder and make India Thalassemia-free, said a press release.

As on August 2022, Eight hospitals to set up committees to decide on applications for aid to treat rare diseases

The Union health ministry has asked eight designated hospitals that treat rare diseases to set up an expert committee each, which will decide on providing the cash aid of Rs 50 lakh within a month of receiving an application for financial assistance from a patient. The eight Centres of Excellence (CoEs) will also be given one-time financial support up to Rs 5 crore for procurement of equipment for strengthening patients care services for screening, diagnosis and prevention (prenatal diagnosis) for rare diseases based on a gap analysis, according to the new guidelines issued by the health ministry.

The ministry on August 11 issued the guidelines and procedures for granting financial assistance to patients suffering from rare diseases as thalassemia, haemophilia, and sickle cell anaemia under the National Policy for Rare Diseases (NPRD), 2021. The ministry on May 19 increased the financial support from Rs 20 lakh to Rs 50 lakh for patients belonging to all categories of rare diseases.

According to the guidelines, a 'Rare Disease Committee' is to be constituted in each CoE. The nodal officer for rare disease of the hospital will be the member secretary of the committee and the CoE may also opt for an outside expert on the panel, if required. The applications received from the patients or guardians will first be scrutinized by the nodal officer, and thereafter placed before the committee for consideration and approval.

The committee will take decision for treatment and fund allocation within four weeks of receiving the application. The employees of central / state government / PSUs / autonomous bodies / statutory bodies and their family, who are beneficiary under any Central government scheme, such as CGHS/EHS etc., state government health scheme and any other scheme of PSUs / autonomous bodies/statutory bodies, will not be eligible for getting financial assistance as per NPRD, 2021.

There will be no reimbursement of expenditure already incurred. Families covered under Ayushman Bharat - Pradhan Mantri Jan Arogya Yojna (AB-PMJAY) will also be eligible for financial assistance as per NPRD, 2021, if the disease is not covered under AB-PMJAY packages. The guidelines mentioned that a maximum financial assistance admissible under the scheme will be up to Rs 50 lakh per patient and the financial aid will be given to the concerned CoE, where the patient is getting treatment / admitted for treatment. The financial assistance shall not be given to the patient directly, the ministry said. As envisaged in the policy, the state governments shall support patients of such rare diseases (listed in Group 2) that can be managed with special diets or hormonal supplements or other relatively low cost interventions. The guidelines also mention about the crowdfunding portal, which was setup in August last year for receiving such fund for patients suffering from rare diseases. Keeping in view the resource constraint and compelling health priorities, it will be difficult for the government to fully finance the treatment of high cost rare diseases. The gap will be filled up by providing financial assistance through crowdfunding, the guidelines said, adding a crowdfunding portal "http://rarediseases.nhp.gov.in has already been created for receiving such fund, the guidelines read.

The CoEs will share information relating to the patients, diseases from which they are suffering and estimated cost of treatment on the crowd-funding portal. The CoEs have the option to explore the possibility of getting financial assistance from other agencies / drugs manufacturers / corporate sector under CSR by signing of MoU.

The NPRD-2021 provides for a hospital-based National Registry for Rare Diseases at the ICMR. The registry is expected to yield information on hospital-based data and disease burden. To streamline the process of capturing data related to various rare diseases, CoEs have been asked to register itself on the ICMR registry immediately.

There are three groups in which patients diagnosed with rare diseases have been classified. The group 1 includes disorders amenable to one-time curative treatment while Group 2 includes diseases requiring long term lifelong treatment having relatively lower cost of treatment and benefit has been documented in literature and annual or more frequent surveillance is required. Under group 3 falls those diseases for which definitive treatment is available but challenges are to make optimal patient selection for benefit, very high cost and lifelong therapy.

The eight CoEs are AIIMS, New Delhi; Maulana Azad Medical College, New Delhi; Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow; Post Graduate Institute of Medical Education and Research, Chandigarh; Centre for DNA Fingerprinting and Diagnostics with Nizam's Institute of Medical Sciences; King Edward Medical Hospital, Mumbai; Institute of Post Graduate Medical Education and Research, Kolkata; and Centre for Human Genetics with Indira Gandhi Hospital in Bengaluru.

DAHOD HEALTH DEPT INITIATIVE: High-performance machine to fight sickle cell disease-

The outreach programme involves mass testing to diagnose SCD, a common monogenic disorder due to autosomal recessive inheritance, is focusing on sickle cell trait screening and genetic counselling before marriage.

To strengthen its fight against Sickle Cell Disease (SCD), the Dahod district health department is procuring its first-ever High-Performance Liquid Chromatography (HPLC) test machine to improve the management and control of the disease in the tribal district.

The outreach programme involves mass testing to diagnose SCD, a common monogenic disorder due to autosomal recessive inheritance, is focusing on sickle cell trait screening and genetic counselling before marriage. Dahod, which has a high incidence of Sickle Cell Disease, has so far, not been able to conduct HPLC tests to ascertain the numbers.

However, with a more receptive tribal population, programme officer for SCD and Epidemic Medical Officer, Dahod, DrNayan Joshi, says the district is now preparing to gather definite data on the disease and test those who have Dithionite Tube Turbidity (DTT).

Dr Joshi said, "So far, we do not have definite comparative data in the district because there was no HPLC machine that could help ascertain the exact number of persons with sickle cell and those who are carriers of the trait... Individuals, who test positive for DTT — the primary screening method in mass testing — can also just be carriers of the trait. The district health department has issued a tender for the procurement of the HPLC machine."

As part of the mass testing of 4,800 students in 15 tribal schools for the Azadi ka Amrut Mahotsav event, 546 students turned out to be DTT positive. In another general camp with an 18,000 testing, 1,190 persons tested positive for DTT and when some of the samples were sent for HPLC testing, 41 turned out to be diseased. On World Sickle Cell Day on June 19, the department conducted a camp for 360 pregnant women and 145 close family members, where 193 persons tested positive for DTT.

"We send some of the samples of those who test positive for DTT for HPLC test to Gandhinahar or Godhra in Panchmahal. We focus on counselling of families to ensure primary testing for all and also prenatal diagnosis for young couples who are trait carriers," said Joshi.

The health department has begun consistent counselling of tribal families to discourage marriages of persons with sickle cell or traits, given that a majority of the younger generation of tribals from the district migrate to other parts for work.

Joshi said, "This week, we held a camp for health workers, making them aware of the factors involved in the inheritance of the disorder from parents... We have been conducting this counselling for tribal couples and families on a routine basis, encouraging soon-to-be-married couples to come and test for sickle cell."

Joshi explains that like any genetic disorder, if both parents are carriers of the sickle cell trait, then the child has a 25% chance of inheriting it.

He said, "For many years, tribals lived unaware that there is a 25 per cent chance of the offspring being diseased, 50% chance of the offspring being a carrier of the trait, and only 25% chance of the child being normal. Now, as awareness has increased, they understand the importance of testing."

The work on sickle cell awareness took a hit during the Covid-19 pandemic but the department, which has 33 sickle cell counsellors now, is back focusing on ante-natal care and encouraging those children born after 2012 to be screened.

In July 14, 2022 then VP inaugurated Blood Transfusion Unit and Advanced Diagnostic Laboratory at the Thalassemia and Sickle Cell Society in Hyderabad

The Vice President, Shri M. Venkaiah Naidu highlighted the importance of preventive measures to address the huge burden of genetic diseases like thalassemia and sickle cell anemia in the country. He wanted the states to undertake mass screening of the children for early identification and management of genetic disorders.

Addressing a gathering after inaugurating the Research Laboratory, Advanced Diagnostic Laboratory and 2 Blood

Transfusion Unit at the Thalassemia and Sickle Cell Society (TSCS) in Hyderabad, the Vice President urged the private sector and NGOs to complement the government's efforts in combating genetic diseases. Recognizing that the available treatment options for these genetic conditions--bone marrow transplantation or regular blood transfusion - are cost intensive and distressing to the child, Shri Naidu called for a comprehensive approach to address the health challenge of Thalassemia and sickle cell anemia.

Mentioning that around 10-15 thousand babies are born every year with Thalassemia in India, the Vice President said that lack of awareness on these genetic diseases is a major impediment in their prevention and early diagnosis. Therefore, he urged all stakeholders – doctors, teachers, public figures, community leaders and media – to spread awareness on Thalassemia and sickle cell disease.

Complimenting TSCS for providing free treatment to patients suffering from these genetic diseases, Shri Naidu wanted the private sector to set up more diagnosis and treatment facilities, especially in tier two and three cities and rural areas to make healthcare accessible to all.

Describing gene disorders a major health concern in the country, the Vice President said that they impose a heavy economic and emotional burden on the affected families. Statistics show that prevalence of beta- Thalassemia is in the range of 2.9 to 4.6% in India whereas sickle cell anemia is more prevalent among lower socio-economic sections of society, ranging from 5 to 40 % among the tribal populations. He said that early detection of genetic disorders will help in counseling the patients, thus avoiding marriage of two individuals who are silent carriers of defective genes which may lead to serious genetic abnormalities in their children.

Noting that children affected with Thalassemia need regular blood transfusions throughout their life, Shri Naidu exhorted the youth to come forward and donate blood for the needy. He also appreciated the Union Health Ministry for coming up with detailed guidelines for prevention and management of Thalassemia, Sickle cell anemia and other variant anemia.
The Vice President praised the members of Thalassemia and Sickle Cell Society for their noble work towards eradicating these diseases from the country. Stating that 'share and care' is the core of Indian philosophy, he wanted everyone to inculcate the values of service mindedness and concerns for others, particularly for weaker sections. "Serving the poor is serving the God," he stressed. On this occasion, Shri Naidu also inaugurated the Main Auditorium and Mini Auditorium at TSCS.

Shri Chandrakant Agrawal, President, Thalassemia and Sickle Cell Society, Smt. Ratnavali K., Vice President, TSCS, Dr. Suman Jain, Chief Medical Research Officer and Secretary, TSCS, Ms. AzraFathima, Clinic Psychologist, TSCS, donors of the Society, doctors, and other eminent personalities attended the event.

TESTIMONIALS

My daughter Alisha is 17 years old. I am giving blood transfusion to her since she was 6 months old at Thalassemia and Sickle Cell Centre run by Dr. Vinky Rughwani. He is just like a god for us as we get blood transfusion, medicines, investigations everything free at his hospital since years. He considers my daughter and all of us as his family members.
--Shahina Attari

My daughter Yogita is 6 years old. We were tired of giving blood to my daughter again and again and luckily she got a single match with her brother but Bone Marrow Transplantation cost is Rs. 15,00,000/-. Dr. Vinky Rughwani, President of Thalassemia and Sickle Cell Society of India made all our expenses available to us at the earliest through Sankalp India Foundation and other organizations. Our daughter underwent Bone Marrow Transplantation. Today she is completely healthy. For that I would be very grateful to Dr. Vinky Rughwani.
-- Bhagwat Nishad

CONTACT DETAILS:

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PHOTO GALLERY

Dr. Vinky Rughwani accepting Covid Yodhdha Puraskar
by Governor of Maharashtra Hon'ble Shri. Bhagat Singh Koshyari ji

Dr. Vinky Rughwani felicitating Governor of Punjab
Hon'ble Shri. Banwarilalji Purohit

Thalassemia and Sickle Cell Centre being inaugurated at the hands
of Chief Minister of Maharashtra Hon'ble Shri. Devendraji Fadnavis

Submitting Memorandum to
Home Minister Rajnath Singhji in presence of Shri. Nitinji Gadkari

Dr. Vinky Rughwani receiving Award from Mayor of Nagpur City

Dr. Vinky Rughwani felicitated by Indian Medical Association

Thalassemia Major and Sickle Cell Trait Camp held on
Thalassemia and Sickle Cell Centre

Dr. Vinky Rughwani with patients of Thalassemia
On World Thalassemia Day Programme

PHOTO GALLERY

World Thalassemia Day Programme held at Thalassemia and Sickle Cell Society of India

Thalassemia Minor and Sickle Cell Trait Camp

Free HLA Matching Camp held at Thalassemia and Sickle Cell Centre

Dr. Vinky Rughwani with Thalassemia Major and Sickle Cell patients

Some of the Press Release

मेधावी छात्रों का रुघवानी के हाथों सत्कार

देश में 1% से भी कम लोग करते हैं रक्तदान

विश्व रक्तदाता दिवस मनाया

Sindhi Vikas Parishad to meet CM to press its demands

एचएलए मैचिंग शिविर का सफल आयोजन

समाज ने तय किया तो 10 वर्ष में सिकलसेल पर नियंत्रण संभव