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Ministry of Tribal Affairs

M/o Tribal Affairs organises the second National Conclave on Sickle Disease in India on World Sickle Cell on 19th June, 2021

Unmukt project to eliminate Sickle Cell Disease launched

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To commemorate the World Sickle Cell Disease Day on 19th June 2021, the Ministry of Tribal Affairs (MOTA) organized the **Second Online National Conclave on 'Sickle Cell Disease in India'**, in partnership with FICCI, Novartis, Piramal Foundation, Apollo Hospitals, NASCO and GASCO.

The event brought together a group of experts on Sickle Cell Disease across India to deliberate on recent advances in Sickle Cell Disease management -- ranging from early diagnosis to latest medicines and advances in treatment of disease.



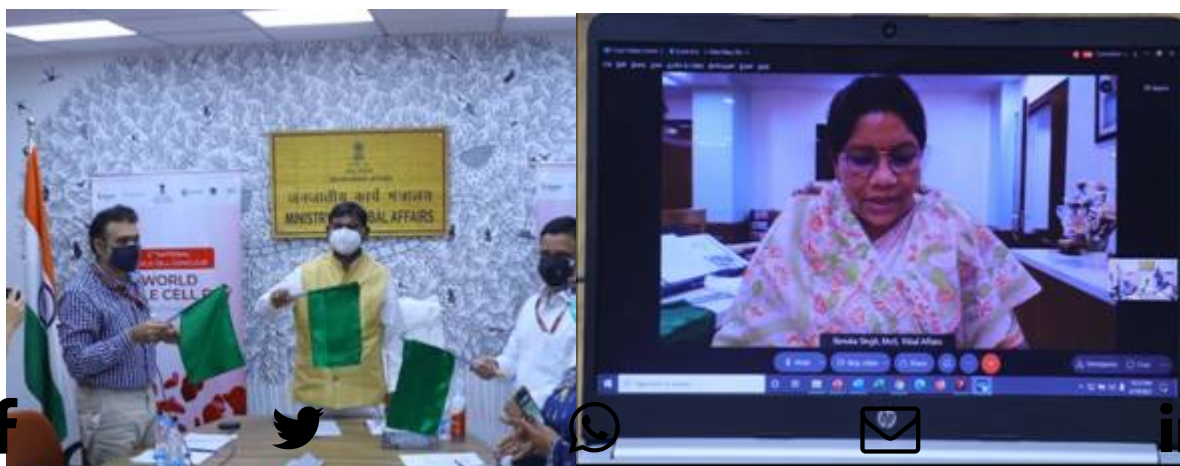


Shri Arjun Munda, Union Minister and Renuka Singh Sauta flagged off mobile vans under **Unmukt project** for strengthening screening and timely management of SCD in Khunti district of Jharkhand and Kanker in Chhattisgarh, 2 tribal districts with high prevalence of sickle Cell disease among tribals.

Shri Munda discussed initiatives taken by Tribal Affairs Ministry by formation of National Council on Sickle Cell Disease and establishment of Tribal Health Cell, which would coordinate with Ministry of Health and State Governments. Shri Munda stressed on need of real time data which provides relevant information related to Sickle Cell patients and their needs in respect of testing, drugs and other infrastructural requirements. He said Tribal Affairs Ministry has devised mechanism for making Central Repository of data through development of Sickle Cell Support Corner which is posted on Ministry's dashboard.

"We need to ensure that the coming generations of tribal population are free from this disease," he said

The Minister added that the Ministry had taken a note of the challenges faced by the patients having limited validity under Rights of Persons with Disability Act. He thanked Ministry of Social Justice and empowerment for increasing validity of disability Certificate from 1 year to 3 year.





Smt Renuka Singh, Minister of State, MOTa, said that SCD is affecting more women and children and nearly 20 per cent of tribal children with SCD die before reaching the age of two, and 30% children die before reaching adulthood. She stressed on the need for reinforcing awareness and prevention following simple yet innovative measures to tackle SCD. She highlighted an urgent need for multi-stakeholder engagement as well as meaningful partnerships with like-minded organizations, pharmaceutical industries, private organizations, not-for-profit organizations for working jointly to reduce morbidity and mortality from SCDs and increasing the access to care for SCD in tribal regions of India.

Shri Anil Kumar Jha, Secretary, MoTA, Government of India stated that Ministry in coordination with Ministry of Health and Family Welfare and States would ensure that facilities for diagnosis and treatment of SCD are available even at PHC level. He also said that all advancements in the treatment of SCD should be available to tribal patients. He highlighted the need of awareness and training programs and appreciated the efforts of partner organisations associated with Ministry in this pursuit.

Dr. Naval Jit Kapoor, Joint Secretary, MoTA, Government of India presented the issues concerning data, Testing, Infrastructure, Awareness program, Training and said Ministry is drafting guidelines and Standard Operating procedure on SCD in collaboration with Health Ministry. He also briefed on action plan prepared by Ministry for the next 1 year.

Dr Arvind Lal, Chair-FICCI Swasth Bharat Task Force and Executive Chairman, Dr Lal Path Labs, Dr Ararup Das, Director, ICMR-NIRTH, Dr Anurag Agarwal, Director, CSIR, Institute of Genomics and Integrative Biology. Dr Shailendra Hegde, Senior VP, Piramal Foundation, Mr Kevin Zou, Head of Oncology, Asia Pacific Cluster, Novartis, and Ms Mary Ampomah, President and CEO, Global Alliance of Sickle Cell Disease Organization (GASCDO) also shared their views on SCD.



The Conclave featured an enlightened panel discussion on 'Multiple faces of Sickle Cell Disease' which included Dr Vinita Srivastava- Advisor, Tirbal Health Cell, Dr Tulika Seth, Professor-AIIMS; Dr Aarup Das, Director, ICMR-NIRTH Jabalpur, Madhya Pradesh; Dr Anupam Sachdeva (HOD, Dept. of Pediatric Haematology, Sir Gangaram Hospital, Delhi); Dr Arvind Neral, Director General, SCIC, Raipur; Dr Ruby Khan, Deputy Director, Blood Cell, Madhya Pradesh; Dr P.K Mohanty, HoD General Medicine & Project Coordinator, Sickle Cell Institute VSSIMSAR, Burla, Odisha, Dr NandithaChowhan, Deputy Director, Blood Cell NHM, Telangana; Dr Umang Mishra, SCD control program project officer, Blood Cell, Gujarat; Mr GautamDongre, Secretary, NASCO; Dr Suresh Sethi, MD &CEO NSDL; Dr AlkaJatkar, Associate Professor Gynaecology, Government Medical College, Nagpur, Maharashtra, Prof, Dipty Jain, HOD, Department of Pediatrics, GMC, Nagpur, Maharashtra and Shri SaumilMody, General Manager, Novartis Oncology India.

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