

National Thalassemia Welfare Society Organizes the 25th International Thalassemia Day

06 May 2019 | News

The event also saw the support of corporate like TCS, Sodexo HCL, Soil, Walmart, Jaquar and RNA Technology



National Thalassemia Welfare Society organized recently the “25th International Thalassemia Day” at Constitution Club, New Delhi.

The event was inaugurated by the Chief Guest TD Dhariyal commissioner disability Govt. of Delhi. He threw light on Thalassemia and RPWD Act 2016.

He said that “Thalassemia, Sickle Cell Anemia and hemophilia have been included in the RPWD Act 2016. Now Thalassemics comes 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.”

Vinita Srivastava, National Senior consultant & coordinator Blood cell – NHM was Guest of honour for the event. She 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 corporate like TCS, Sodexo HCL, Soil, Walmart, 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, General Secretary, National Thalassemia Welfare Society thanked Vinita Srivastava 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, “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 Vinita Srivastava to get it notified at the earliest. Dr Arora also requested 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 we see only one or two chelators available.

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.

Anurag Krishna CSR Lead - North TCS, Mr Sandeep Kumar Head HR Operations – Sodexo; Rajiv Kumar HR Head HCL infotech Ltd; AN Bhattacharya, Professor & Chair, Marketing & Social Innovation- SOIL; Sunita Patnaik General Manager Walmart; Kanwar Shamsheer Relan, Head CSR- Jaquar Foundation and Rachna Bakhru, Partner - RNA Technology & IP Attorneys were present.