Civil society members seek inclusion of Thalassemia in all political party manifestos
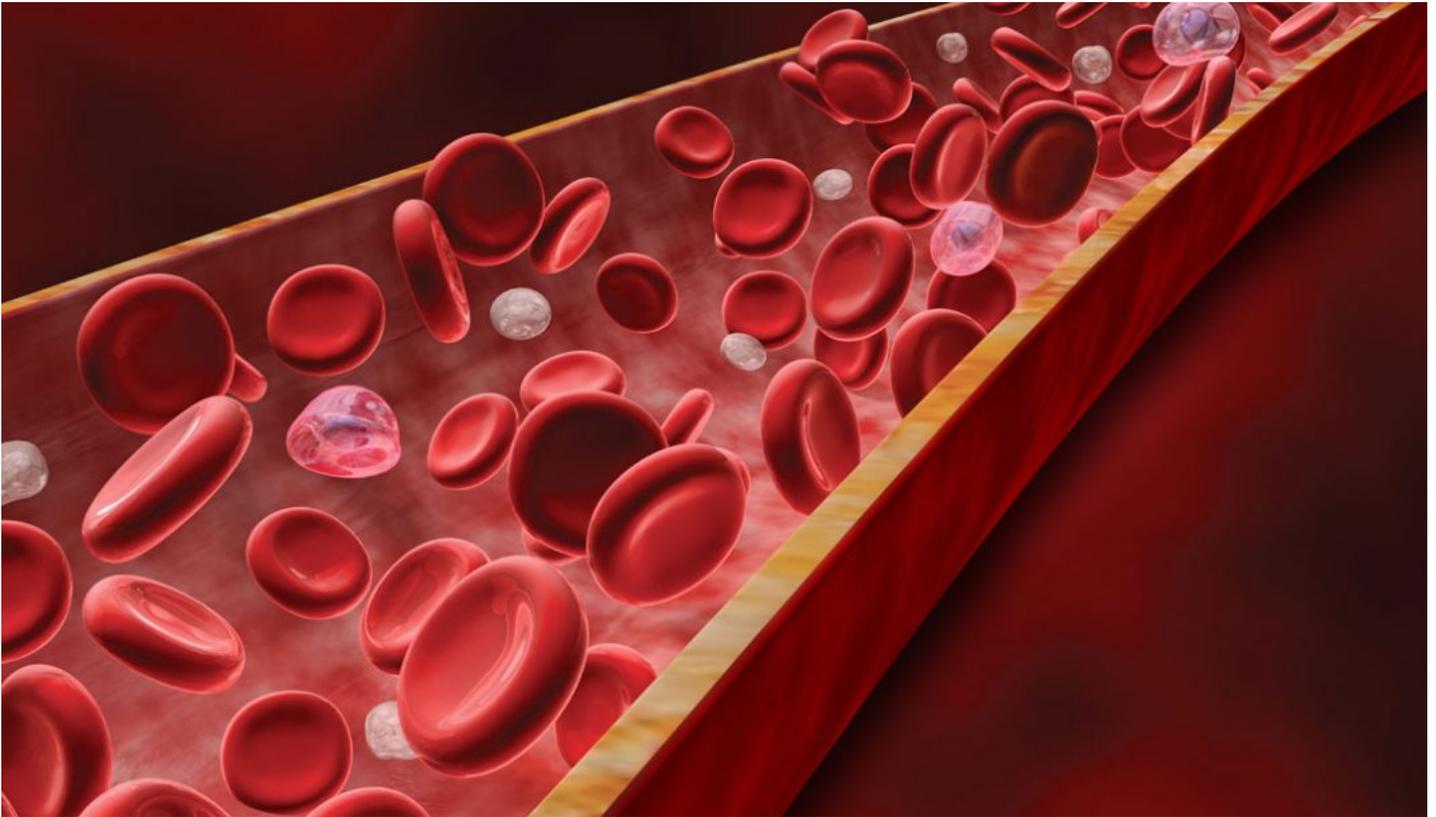
https://www.biovoicenews.com/civil-society-members-seek-inclusion-of-thalassemia-in-all-political-party-manifestos/

By : BioVoice Correspondent - March 14, 2019

New Delhi: With a population of 1.3 billion people and about four per cent of them being Thalassemia minors, India has the highest number of Thalassemics in the world. A huge 50 million people are at risk but oblivious to the possibility of facing a distressing situation when they marry and start a family.

In this backdrop, Civil Society members have sought the inclusion of a charter of 10-points that 'demands to achieve Zero Thalassemia by 2022' in the election manifestos of all political parties in India.

"In the run up to the General Election 2019, we concerned citizens, parents and patients hereby request all political parties to consider the inclusion of 10-point demands in the respective party manifestos for India to achieve Zero Thalassemia by 2022. This is achievable and we look forward to India becoming free of Thalassemia in the years to come," reads the 8-page Charter released at New Delhi.

Brought out by Amit Iyer Memorial Foundation, Mumbai, Sankalp India Foundation, Bangalore, Centre for Legislative Research and Advocacy (CLRA), New Delhi, WE CARE Trust, Mumbai, JAS Trust Ahmadabad, and Institute of Poverty and Governance, New Delhi,

the manifesto urges that for a Thalassemia Free India, an effective prevention programme should include a wide public awareness campaign by using various media so that every woman is empowered to ask for a Thalassemia screening test at her first pregnancy. The manifesto also demands a legal mandate for gyneacologists to test every woman at the first pregnancy.

Thalassemia Major, an inherited blood disorder results in excessive destruction of red blood cells, which leads to anemia where the body doesn't have enough healthy red blood cells. A few months after birth, the child starts looking pale, is not very active and is sickly. To survive, one needs to get blood transfusions every two-three weeks for the entire life span.

Prolonged blood transfusions and other treatments give rise to complications needing periodic regular medical monitoring of serum ferritin (iron overload level) and, functioning of organs like liver, spleen, heart, etc. The risks of infections like HIV, Hepatitis B and C, etc. is not uncommon. Thus a life-long comprehensive Thalassemia care programme is required for the child to lead a near normal life.

The Charter also lists that Thalassemia should be declared as a National Public Health Challenge by the Government; creation of a national register of Thalassemia majors, Thalassemia minors and providing a technology-based system to collect and collate virtual and real-time data on Thalassemia; Providing encouragement to the existing Thalassemia major children and adults to pursue education and careers without discrimination – not only top-class comprehensive care facilities but also extending travel concessions, rebate in school/college fees, etc.

Since presently the only cure available for existing Thalassemia major population is Bone Marrow Transplant (BMT), only a fraction of them are able to access as they need HLA (human leukocyte antigens) matched donor. Despite the fact that there are many centres in the country where BMT is available, affordability becomes prohibitive as the cost of such a transplant ranges from Rs 9 to 20 lakh. Therefore, the Charter demands for "one or two BMT centres in every State in order to subsidise the cost of BMT for a Thalassemic to make it absolutely free".

"If the country can have a law to prevent female foeticide, why can't we have a law to prevent thalassemia and spare 10 to 12 thousand newborns lifelong suffering?" says Sundaresan Iyer, whose son, a thalassemia major, died at the age of 18 years, but ironically, he became a victim of HIV infection acquired due to repeated blood transfusions and he departed for his heavenly abode in 1997.