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Celebrating
25 Years of CARING
8th National Thalassemia Conference

**“THE RIGHTS
OF PERSONS WITH
DISABILITIES
ACT**

What it means to you



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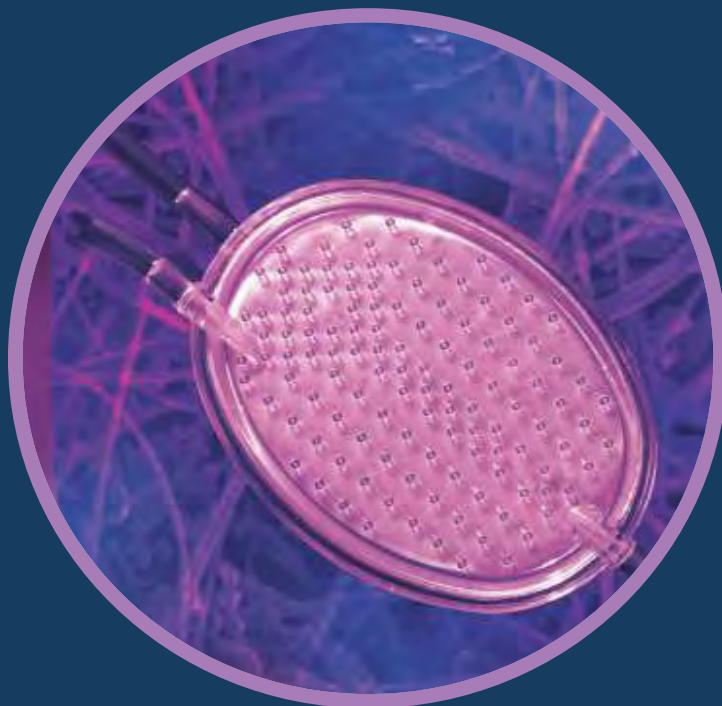
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Dear Friends

Many of you may be aware that first “Persons with Disabilities (PWD) Act” was passed in Dec 1995 and notified on 1st Jan 1996. Seven disabilities were covered under that act but not thalassemia. Persons affected with 7 notified disabilities were not happy with the Act and demanded some amendments.

Under the guidance of our president Saini Ji I grabbed this opportunity to fight for inclusion of Thalassemia in the list of disabilities through the amendments. I started interacting with the Ministry of Social Justice & Empowerment (MOSJE) and activists from other disabilities to recommend inclusion of thalassemia in the list of disabilities for the purpose of PWD Act.

An amendment committee was formed under the chairmanship of Dr Amita Dhanda to review and recommend amendments in the said act. President NTWS Km. Surrender Saini ji was one of the eight members of this committee. I fought a hard core battle for inclusion of Thalassemia and Haemophilia in the list of disabilities for the purpose of PWD act. Participated in most of the meetings held by this committee and discussions held by united front formed by disabled persons across the disability groups. Innumerable correspondence was done with PMO, Ministers and secretaries of MOSJE and other disability groups to get their support. Finally the committee submitted its report on 5th March 1999 and recommended inclusion of Thalassemia and Haemophilia in the list of Disabled. Saini Ji's support was major factor in achieving this milestone. However committee did not recommended for reservation in education and jobs but inclusion for other benefits was a moment of solace for us to continue our fight further.

After that, many deliberations were held amongst the authorities and disabled groups to finalise the amendments. The bill was ready by January 2014. It was a blessing by the almighty that “Rights of Persons with Disabilities (RPWD) Act 2016” was passed on 16th Dec' 2016, on the eve of our 8th National Thalassemia Conference, a mega event organised to mark the concluding ceremony of our silver jubilee celebrations.

According to my information apropos to this act (RPWD Act 2016) two thalassemia patients got admission in Delhi University. I was directly involved in pursuing their admission under PWD Act. Two thalassemics got nod from courts for admission in MBBS course, one from Chhattisgarh under Hon'ble Supreme Court's order and another at Guru Gobind Singh Indraprastha University under directions from Hon'ble Delhi High Court.

Rules pertaining to RPWD Act 2016 were notified on 15th June 2017. As the RPWD Act and its rules are comprehensive and may not be understood by all, I have tried to summarize the important points relevant to Thalassemia and other blood disorders. I hope this exercise will be fruitful and beneficial to all. Process of obtaining disability certificate and forms for application and issue of certificate have also been published to make the process easy.

Thalassemia associations are requested to send their activity report with photos for publication in FIT BULLETIN

प्रिय मित्रों

आप में से कई लोग जानते हैं कि पहले “पर्सन्स विद डिसेबिलिटीस (पीडब्ल्यूडी) अधिनियम” 1995 में पारित किया गया था और 1 जनवरी 1996 को अधिसूचित किया गया था। सात दिव्यांग अवस्थाओं को अधिनियम के तहत सम्मिलित किया गया था लेकिन थैलासीमिया को नहीं। 7 अधिसूचित दिव्यांगों से प्रभावित व्यक्ति अधिनियम से खुश नहीं थे और वो कुछ संशोधन चाहते थे।

हमारी अध्यक्षा कुमारी सुरेंद्र सैनी जी के मार्गदर्शन में मैंने संशोधनों के माध्यम से थैलेसीमिया को दिव्यांगों की सूची में शामिल करने के लिए लड़ने का अवसर उपयोग किया। सामाजिक न्याय और अधिकारिता मंत्रालय (डैश्रम) और अन्य दिव्यांगों के कार्यकर्ताओं से पीडब्ल्यूडी अधिनियम में संशोधनों के उद्देश्य के लिए दिव्यांगों की सूची में थैलासीमिया को शामिल करने की सिफारिश करने के लिए बातचीत शुरू कर दी।

समीक्षा करने के लिए डॉ अमिता ढांडा की अध्यक्षता में एक संशोधन समिति का गठन किया गया और इस अधिनियम में संशोधन की सिफारिश करने के लिए कहा गया था।

NTWS अध्यक्षा सैनी जी इस समिति के आठ सदस्यों में से एक थी। मुझे पीडब्ल्यूडी अधिनियम के उद्देश्य के लिए दिव्यांगों की सूची में थैलासीमिया और हीमोफिलिया को शामिल करने के लिए एक कठिन संघर्ष करना पड़ा। मैंने इस समिति द्वारा आयोजित अधिकांश बैठकों में भाग लिया और दिव्यांग समूहों में दिव्यांग व्यक्तियों द्वारा बनाई गई संयुक्त मोर्चा द्वारा आयोजित चर्चाओं में अपने पक्ष को मजबूती से रखा। अपने समर्थन पाने के लिए प्रधान मंत्री कार्यालय, मंत्रियों और सामाजिक न्याय और अधिकारिता मंत्रालय के सचिवों और अन्य दिव्यांग समूहों के साथ अनगिनत पत्राचार किया। अंत में समिति ने 5 मार्च 1999 को अपनी रिपोर्ट पेश की और दिव्यांगों की सूची में थैलासीमिया और हीमोफिलिया को शामिल करने की सिफारिश की। इस लक्ष्य को प्राप्त करने में सैनी जी का मुख्य सहयोग रहा। हालांकि समिति ने शिक्षा और नौकरियों में आरक्षण के लिए सिफारिश नहीं की लेकिन अन्य लाभों को शामिल करने से यह हमें हमारी लड़ाई को जारी रखने के लिए सात्वना का एक क्षण था

संशोधन के अंतिम स्वरूप में अधिकारियों और विकलांग समूहों के बीच कई बार विचार-विमर्श हुआ। जनवरी 2014 तक बिल तैयार था। सर्वशक्तिमान ईश्वर के आशीर्वाद द्वारा “दिव्यांग व्यक्तियों के अधिकार (आरपीडब्ल्यूडी) अधिनियम 2016”, हमारे रजत जयंती उत्सव के समापन समारोह के लिए आयोजित 8 वें राष्ट्रीय थैलासीमिया सम्मेलन की पूर्व संध्या पर, 16 दिसंबर 2016 को पारित किया गया।

मेरी सूचना के अनुसार इस अधिनियम (आरपीडब्ल्यूडी अधिनियम 2016) के अनुरूप दो थैलासीमिया के मरीजों को दिल्ली विश्वविद्यालय में प्रवेश मिला है। इस प्रवेश के तहत मैं प्रत्यक्ष रूप में शामिल था। दो थैलासीमिक्स को एमबीबीएस कोर्स में प्रवेश के लिए आदेश मिला है, एक माननीय सर्वोच्च न्यायालय के आदेश के तहत छत्तीसगढ़ में और एक गुरु गोबिंद सिंह, इंदरप्रस्था विश्वविद्यालय में, माननीय दिल्ली उच्च न्यायालय के निर्देशों के तहत।

आरपीडब्ल्यूडी अधिनियम 2016 से संबंधित नियम 15 जून 2017 को अधिसूचित किये गए। जैसे कि आरपीडब्ल्यूडी अधिनियम और उसके नियम व्यापक हैं और सभी के द्वारा समझे नहीं जा सकते, अतः मैंने थैलेसीमिया और अन्य रक्त विकारों से संबंधित महत्वपूर्ण बिंदुओं को संक्षेप में प्रस्तुत करने का कुछ प्रयास किया है। मुझे उम्मीद है कि यह परिश्रम फलदायी होगा और सभी के लिए फायदेमंद होगा। दिव्यांगता प्रमाण पत्र प्राप्त करने की प्रक्रिया, आवेदन पत्र और प्रमाण पत्र जारी करने के लिए आवश्यक फार्म भी प्रकाशित किए गए हैं।

आप में से कई लोग जानते हैं कि पहले “पर्सन्स विद डिसेबिलिटीस (पीडब्ल्यूडी) अधिनियम” 1995 में पारित किया गया था और 1 जनवरी 1996 को अधिसूचित किया गया था। सात दिव्यांग अवस्थाओं को अधिनियम के तहत सम्मिलित किया गया था लेकिन थैलासीमिया को नहीं। 7 अधिसूचित दिव्यांगों से प्रभावित व्यक्ति अधिनियम से खुश नहीं थे और वो कुछ संशोधन चाहते थे।

Regular blood transfusion is the life line for all children with thalassemia major. Repeated blood transfusion results in iron overload which forms the major cause of morbidity and mortality. All thalassemic children will succumb to the disease in second decade of life, primarily due to cardiac failure or cirrhosis of liver if the iron overload is left untreated. Institution of adequate chelation therapy with the current protocols therapy along with regular blood transfusions to maintain pre-transfusion hemoglobin level of 10 gm/dl has improved the survival. Presently thalassemic children lead a normal life as was evident from multi-centric studies of 7 centers where over 90% of children born after 1980 (Fig 1). Adherence to adequate chelation therapy plays a key role for long term survivals.

Deferasirox dispersible tablets (DT) were approved in 2005 after extensive clinical trials in over 100 countries worldwide. Over the last 12 years it has evolved as a gold standard therapy. It became an ideal iron chelator as it was

- a) effective oral iron chelator
- b) it has high affinity for iron
- c) has prolonged half-life (12-16 hours) and thus it is effective as single daily dose
- d) it is lipid soluble and able to enter cardiac and hepatic cells easily to chelate iron
- e) palatable
- f) acceptable side effects
- g) cheap drug so that it is affordable by majority

Majority of thalassemic children even in developed countries shifted to deferasirox from desferrioxamine therapy which is injectable needing prolonged administration with help of infusion pump. It was expensive and had several side effects. Deferiprone was the first oral chelator but had significant side effects such as joint pains, low white cell count and platelets. It needed to be administered orally in three doses and needs regular blood monitoring (CBC) every month.

Deferasirox has long half-life of 12-16 hours and lipid soluble with high affinity for iron. It excretes iron primarily through stools. It is available in tablet form which can be dispersed in water or apple juice using a non-metallic stirrer and can be consumed as a drink once daily. As the drug is lipid soluble it enters cells of liver, heart, etc easily and is able to mobilize iron from these tissues effectively. Deferasirox over the year has become gold standard therapy and a drug of choice as oral iron chelator. This drug has acceptable side effects which included diarrhea, nausea, abdominal pain, vomiting, headache, constipation; in varying proportion in different studies. Deferasirox also causes transient rise in blood urea, serum creatinine, transaminase levels which are dose dependent however these changes are not alarming. Maximum dose recommended is 40 mg/kg/day. Higher dose are not recommended because of various side effects. Children with

higher ferritin levels are given combination therapy as the dose of deferasirox cannot be increased significantly. Over the years Deferasirox dispersible tablet (DT) are being recommended as effective chelating agent with acceptable safety. This drug is generally well tolerated and has improved the quality of life to greater extent. However there are problems of long term adherence to deferasirox DT such as palatability, gastrointestinal side effects and many children do not tolerate this drug and have shifted to other chelating drug either singly or combination therapy. Combination therapy is also recommended when any single chelating agent is unable to induce negative iron balance. Sub optimal chelation therapy results in various complications and high risk of morbidity and mortality at younger age (Table 1). A new deferasirox film-coated tablets (FCT) has been developed with the same active compound. This drug has high bioavailability and can be taken with meals. Since the deferasirox FCT has high bioavailability and therefore its dose is 30% less than DT. It was expected that the side effects deferasirox (FCT) will be less as compared with DT form because of its better bioavailability. In controlled study over 170 cases the efficacy, safety of DT & FCT were compared. This study was presented in American Society Hematology (ASH) in December 2016. It was observed deferasirox FCT is an effective drug with better acceptability with lesser side effects such as abdominal pain, nausea, loose motions, vomitings, constipation and headache etc. as compared with deferasirox DT. Similarly FCT preparation was found to safer for liver and kidney over prolonged duration of study.

Deferasirox FCT is old drug with new carrier which is equally effective, better tolerable with lesser side effects. Hopefully the deferasirox FCT will be of great boon for those thalassemic patients who cannot tolerate deferasirox DT. Adequate chelation therapy is of paramount importance for long term survivals. The improvement in chelating agent will be of great help to thalassemic children to strict to adequate chelation therapy as per current protocols.

Table 1: Morbidity and mortality associated with non -adherence to iron chelation therapy

Outcome measures	Adequate or good chelation adherence	Poor or non -adherence
Survival upto 30 yrs. (%)	90	15
15-year survival (%)	100	52
Life expectancy (yrs)	46.2	22.2
Life time risk of cardiac disease (%)	60	96
Risk of diabetes (%)	9	54
Risk for hypogonadism (%)	47	81
Risk for hypothyroidism (%)	14	28

Huang Vicky et al. Blood 2015; 126:4748.

थैलेसीमिया मेजर वाले सभी बच्चों के लिए नियमित रूप से रक्त आधान जीवन रेखा है। पुनरावर्ती रक्त आधान के परिणामस्वरूप लौह अधिभार रोग और मृत्यु दर का प्रमुख कारण होता है। यदि लोहे का अधिभार बिना इलाज के छोड़ दिया जाता है तो सभी थैलेसिमिक बच्चे जीवन के दूसरे दशक में, मुख्य रूप से हृदय की विफलता या जिगर के सिरोसिस की वजह से बीमारी से ग्रस्त हो जाते हैं और मृत्यु को प्राप्त हो जाते हैं। मौजूदा आदर्शपत्र चिकित्सा के अनुसार पर्याप्त चिलेशन चिकित्सा, नियमित रक्त संचारण के साथ प्री-ट्रांसफ्यूजन हीमोग्लोबिन स्तर को 10 ग्राम/डेसी लीटर बनाए रखने से आस्तित्व में सुधार हुआ है। वर्तमान में थैलेसिमिक बच्चे एक सामान्य जीवन जीते हैं, जैसा कि 7 केंद्रों के बहु-केंद्रित अध्ययन जहां 90% से अधिक बच्चे 1980 के बाद पैदा हुए, से स्पष्ट हुआ है,। पर्याप्त चिलेशन उपचार के प्रति निष्ठा, दीर्घकालिक जीवन के लिए एक महत्वपूर्ण भूमिका निभाता है।

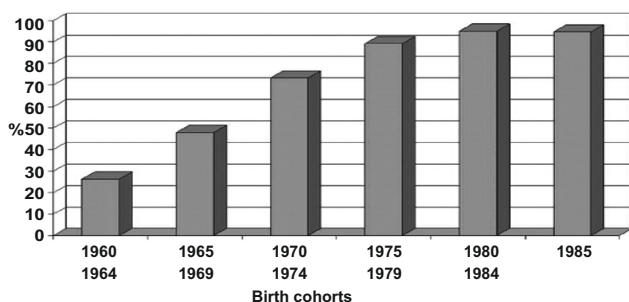
दुनिया भर के 100 से अधिक देशों में व्यापक चिकित्सीय परीक्षणों के बाद 2005 में डेफ्रासीरोक्स घुलनशील गोली (डीटी) को मंजूरी दी गई थी। पिछले 12 वर्षों में यह एक स्वर्ण मानक चिकित्सा के रूप में विकसित हुआ है। यह एक आदर्श लोह निष्कासक बन गया है जैसा कि यह:-

- प्रभावी मौखिक लोह निष्कासक है
- इसमें लोहे के लिए उच्च आकर्षण है
- लंबे समय तक (12-16 घंटे) शरीर में असरकारक है और इस प्रकार यह एक दैनिक खुराक के रूप में प्रभावी है
- यह वसा में घुलनशील है और हृदय तथा यकृत कोशिकाओं में आसानी से प्रवेश करने में सक्षम है और लोहे को घोल के निकलता है
- स्वादिष्ट है
- संतोषजनक दुष्प्रभाव
- सस्ती दवा इसलिए बहुमत के आर्थिक समर्थ में।

विकसित देशों में भी अधिकांश थैलेसिमिक बच्चों को डेस्फैरीओक्सामाइन चिकित्सा, जो इन्फ्यूजन पंप की मदद से लंबे समय तक करनी पड़ती है, से डेफ्रासीरोक्स में स्थानांतरित किया जाता है। यह महंगा था और इसके कई दुष्प्रभाव थे। डेफरिप्रोन पहला मौखिक चिलेटर था, लेकिन इसमें संधियों में दर्द, सफेद कणों और प्लेटलेट की गणना में कमी जैसे महत्वपूर्ण दुष्प्रभाव थे। इसे मौखिक रूप से दिन में तीन बार हर महीने नियमित रक्त निरीक्षण निगरानी (सीबीसी) में देने की आवश्यकता होती है।

डेफ्रासीरोक्स लंबे समय तक (12-16 घंटे) शरीर में असरकारक है और इसमें लोहे के लिए उच्च आकर्षण है के साथ यह वसा में घुलनशील है। यह मुख्य रूप से मल के माध्यम से लोहे को विसर्जित करता है। यह टैबलेट फॉर्म में उपलब्ध

Figure 1: The life of patients with thalassemia major 2009 children over 7 centers



Borgna-Pignatti Caterina. Haematologica. 2010; 95:345-348.

है, जिसे धातु रहित छड़ के जरिये पानी या सेब के रस में घोला जा सकता है और रोजाना एक बार पीने के रूप में उपयोग किया जाता है। जैसा कि दवा वसा में घुलनशील है, यह यकृत, हृदय, आदि की कोशिकाओं में आसानी से प्रवेश करती है और इन ऊतकों से प्रभावी रूप से लोहे को निष्कासित करती है। कुछ वर्षों में डेफ्रासीरोक्स एक स्वर्ण मानक चिकित्सा और मौखिक लोहे के चिलेटर के रूप में पसंदीदा दवा बन गई है। इस दवा को स्वीकार्य दुष्प्रभाव शामिल हैं जिनमें विभिन्न अध्ययनों में विभिन्न अनुपात में दस्त, मितली, पेट दर्द, उल्टी, सिरदर्द, कब्ज शामिल हैं। डेफ्रासीरोक्स रक्त में यूरिया, सीरम क्रिएटिनिन, ट्रांसअमीनेस स्तर में क्षणिक वृद्धि का कारण बनता है, जो दवा की मात्रा पर निर्भर होते हैं, हालांकि ये परिवर्तन खतरनाक नहीं हैं। इसकी अधिकतम खुराक 40 मिलीग्राम/किग्रा/दिन है। विभिन्न दुष्प्रभावों के कारण उच्च खुराक की सिफारिश नहीं की जाती है। उच्च फेरिटिन के स्तर वाले बच्चों को संयुक्त उपचार दिया जाता है क्योंकि डेफ्रासीरोक्स की खुराक में काफी वृद्धि नहीं की जा सकती। वर्षों से डेफ्रासीरोक्स घुलनशील टैबलेट (डीटी) को स्वीकार्य सुरक्षा वाले प्रभावी चिलेटिंग दवा के रूप में अनुशंसित किया जा रहा है। इस दवा को आम तौर पर अच्छी तरह से सहन किया जा सकता है और इससे जीवन की गुणवत्ता में काफी हद तक सुधार हुआ है। हालांकि लंबे समय तक डेफ्रासीरोक्स डीटी के पालन की समस्याओं जैसे कि स्वादिष्टता, जठरांत्र संबंधी दुष्प्रभाव और कई बच्चे इस दवा को बर्दाश्त नहीं करते हैं इस कारण अन्य चिलेटिंग दवा या तो अकेले या संयुक्त उपचार में स्थानांतरित कर रहे हैं। जब कोई एक चिलेटिंग दवा अकेले ऋणात्मक लौह संतुलन उत्पन्न करने में असमर्थ हो तो संयुक्त उपचार की सिफारिश की जाती है। उप-इच्छित चिलेशन चिकित्सा का परिणाम विभिन्न जटिलताओं और कम उम्र में मृत्यु के उच्च जोखिम से भरा होता है।

उसी योगिक पदार्थ के साथ एक नई डेफ्रासीरोक्स फिल्म-लेपित टैबलेट (एफसीटी) विकसित की गई है। इस दवा की उच्च जैवउपलब्धता है और भोजन के साथ ली जा सकती है। चूंकि डेफ्रासीरोक्स एफसीटी में उच्च जैवउपलब्धता है इसलिए इस की मात्रा डीटी से 30% कम है। यह उम्मीद थी कि इसके बेहतर जैवउपलब्धता के कारण डीटी फार्म की तुलना में दुष्प्रभाव डेफ्रासीरोक्स (FCT) में कम होगा। 170 मामलों में नियंत्रित अध्ययन में डीटी और एफसीटी की प्रभावकारिता की तुलना की गई। यह अध्ययन दिसंबर 2016 में अमेरिकन सोसायटी हैमेटोलॉजी (एसएच) में प्रस्तुत किया गया था। इस अध्ययन में यह पाया गया कि डेफ्रासीरोक्स डीटी के मुकाबले पेट में दर्द, मतली, अतिसार, उल्टी, कब्ज और सिरदर्द आदि जैसे दुष्प्रभाव कम होते हैं। बेहतर स्वीकार्यता के साथ डेफ्रासीरोक्स एफसीटी एक प्रभावी दवा है। इसी तरह लंबे अध्ययन के समय तक जिगर और किडनी के लिए डेफ्रासीरोक्स एफसीटी को सुरक्षित पाया गया।

डेफ्रासीरोक्स एफसीटी एक नए वाहक के साथ पुरानी दवा है जो कम दुष्प्रभाव के साथ समान रूप से प्रभावी है और बेहतर सहनीय है। आशा है कि डेफ्रासीरोक्स एफसीटी उन थैलेसिमिक मरीजों के लिए महान वरदान सिद्ध होगी जो डेफ्रासीरोक्स डीटी को बर्दाश्त नहीं कर सकते हैं। लंबे समय तक जीवित रहने के लिए पर्याप्त चिलेशन चिकित्सा सबसे महत्वपूर्ण है। चिलेटिंग दवा में सुधार वर्तमान आदर्श पत्र के अनुसार थैलेसिमिक बच्चों को पर्याप्त रूप से उचित चिकित्सा के लिए अत्यधिक सहायक होगा।

Defrasirox (Film-Coated Tablets)	Defrasirox (Dispersible Tablets)
Oleptiss 360mg	500mg Asunra / Desirox / Defrijet / Desifer
Oleptiss 180mg	250mg „
Oleptiss 90mg	125mg „

What it means to you

The disability act "THE RIGHTS OF PERSONS WITH DISABILITIES ACT, 2016" (NO. 49 OF 2016) was passed in the parliament on 16.12.2016 and notified by the President on 27th December, 2016. The types of disabilities have been increased from existing 7 to 21 and the Central Government will have the power to add more types of disabilities. Thalassaemia, haemophilia and sickle cell disease have been included in the list of disabilities in this act.

Rules were notified by MINISTRY OF SOCIAL JUSTICE AND EMPOWERMENT [Department of Empowerment of Persons with Disabilities (Divyangjan)] on 15th June, 2017

Salient features of this act vis-a-vis Thalassaemia and other blood disorders

- Persons with "benchmark disabilities" are defined as those certified to have at least 40 per cent of the disabilities.

Though guidelines for issue of disability certificate with percentage of disability have not been notified but Supreme Court judgment has clarified that Thalassaemia Major fall under "Benchmark Disability".

How to get certificate of disability (chapter VII of RPWD act 2016)

Application for certificate of disability.- (1) Any person with specified disability may apply in Form -IV (*format printed in this bulletin*) for a certificate of disability and submit the application to -

- (a) A medical authority or any other notified competent authority to issue such a certificate in the district of residence of the applicant as mentioned in the proof of residence in the application; or
- (b) **The concerned medical authority in a government hospital where he may be undergoing or may have undergone treatment in connection with his disability:**

If the person with disability is a minor the application on his behalf may be made by his parent/guardian. The application shall be accompanied by -

- (a) proof of residence;
- (b) two recent passport size photographs; and
- (c) aadhar number or aadhar enrolment number, if any.

Note. - No other proof of residence shall be demanded from the applicant who has aadhar or aadhar enrolment number.

1. Issue of certificate of disability.- (1) On receipt of an application, the medical authority shall, verify the information as provided by the applicant and shall assess the disability in terms of the relevant guidelines issued by the Central Government and after satisfying himself that the applicant is a person with disability, issue a certificate of disability in his favour in Form VII (*format printed in this bulletin*), in cases of thalassaemia haemophilia and sickle cell diseases.

As the guidelines for issue of certificates for thalassaemia in percentage disability have not been notified by the government till the publication of this bulletin, you can ask for disability certificate from your transfusion centre by showing copy of the Supreme Court order which has identified thalassaemia as Benchmark disability

[*supremecourt/2017/22694/22694_2017_Order_11-Aug-2017.pdf*](#).

If you are taking transfusion from private hospital then it has to be counter signed from a Govt. hospital/ CMO of the District.

(2) **The medical authority shall issue the certificate of disability within a month from the date of receipt of the application.**

(3) If an applicant is found ineligible for issue of certificate of disability, the medical authority shall convey the reasons to him in writing under Form VIII within a period of one month from the date of receipt of the application.

2. A person to whom such certificate has been issued shall be entitled to apply for facilities, concessions and benefits admissible for persons with disabilities under schemes of the Government and of non-Governmental organizations funded by the Government.

Benefits available to all persons under "Benchmark Disabilities"

1. Employment-Equal opportunity and Non-discrimination:-

The appropriate Government shall ensure that the persons with disabilities enjoy the right to equality, life with dignity and respect for his or her integrity equally with others. No Government establishment shall discriminate against any person with disability in any matter relating to employment. No promotion shall be denied to a person merely on the ground of disability.

Comments: Now thalasseemics will not have to face problems as we had to face in the case of Dr Anjali Sardana or Mr. Sukhsohit Singh (IAS).

2. Incentives to employers in private sector:- Government and the local authorities shall, within the limit of their economic capacity and development, provide incentives to employer in private sector to ensure that at least 5% of their workers are persons with benchmark disability.

Comments: Even though we don't have privilege of reservation in jobs but still this provision in the act will encourage private employers to employ thalassemics because they are covered under "Benchmark Disability"

3. Education:- The Government and local authorities shall ensure that every child with benchmark disability has access to free education in an appropriate environment till he/she attains the age of eighteen years. Admit them without discrimination and provide education and opportunities for sports and recreation activities equally with others.

Comments: Disabled people start education late and may take more than 1 year in a class thus will not be able to complete even basic education by 18 years of age. Moreover during higher education, the expenses incurred are enormous, this is the time when disabled people require more financial support so right to free and compulsory education should be extended to 30 years. Disability sector across the disabilities have to fight for the same.

4. Reservation in higher educational institutions:- All Government institutions of higher education and other higher education institutions receiving aid from the Government shall reserve not less than five per cent seats for persons with benchmark disabilities. The persons with benchmark disabilities shall be given an upper age relaxation of five years for admission in institutions of higher education.

Comments: One of the major benefits for our class of disability. Two thalassemics got admission in Delhi University and one thalassemic got admission in MBBS in Chhatisgarh through Hon'ble Supreme court order, Another thalassemic in Delhi got orders for admission in IP University, Delhi through Hon'ble high court of Delhi.

5. Social security:- Government shall within the limit of its economic capacity shall formulate necessary schemes and programs to safeguard and promote adequate standard of living to enable them to live independently or in the community. The quantum of assistance to the persons with disabilities under such schemes and programs shall be at least 25% higher than the similar schemes applicable to others.

Disability pension to persons with disabilities subject to such

income ceiling as may be notified. Unemployment allowance to persons with disabilities registered with Special Employment Exchange for more than two years and who could not be placed in any gainful occupation. Care-giver allowance to persons with disabilities with high support needs.

Comprehensive insurance scheme for persons with disability, not covered under the Employees State Insurance Schemes, or any other statutory or Government-sponsored insurance schemes

Comments: This will make the life of Persons with Disabilities of this category a little more comfortable. However we have to study and work out how thalassemics can benefit from this provision.

6. Health:- Provisions of aids and appliances, medicine and diagnostic services and corrective surgery free of cost to persons with disabilities with such income ceiling as may be notified.

Priority in attendance & treatment.

Essential medical facilities for life saving emergency treatment and procedures

Comments: This provision will be very helpful in getting FREE transfusion & chelation including infusion pumps & scalp vein sets as well as splenectomy and bone marrow transplant for all. However income ceiling may be an issue but still even if the upper limit of income remains Rs. 5 lakh (as in case of MOHFW-Coal India CSR project) many families would be benefitted.

There should not be any queue or a separate queue for disabled persons.

Expect better treatment for cardiac & liver emergencies

7. LOAN:- Loans at concessional rates including that of microcredit.

Comments: This provision will be very helpful in getting small loans without any guarantee, employment or verifiable credit history.

8. Prevention:- Government shall take measures and make schemes or programs to promote healthcare and prevent the occurrence of disabilities, screen all the children at least once in a year for the purpose of identifying "at-risk" cases.

Comments: Under this provision Government has to take adequate measures to create awareness at all levels including schools, health care workers, angadwadi workers, village level workers, radio, press and electronic media, training to the staff at the primary health centres; take measures for developing pre-natal diagnostic facilities for prevention & control of thalassemia.

9. Insurance & Rehabilitation: - The Government shall make insurance schemes for their employees with disabilities. The Government and the local authorities may grant financial assistance to non-Governmental Organizations for programs of rehabilitation, particularly in the areas of health, education and employment for all persons with disabilities.

The Government while formulating rehabilitation policies shall consult the non-Governmental Organizations working for the cause of persons with disabilities.

Comments: We will have to ask the Government to make insurance schemes for disabled persons specially persons under this category (blood disorders) who are not employees of any Government or semi-Government organization.

NGOs working in the field of disability (thalassemia) will become stronger in forming policies and their implementation.

10. Special schemes and development programmes:- Government shall make schemes in favour of persons with benchmark disabilities, to provide 5% reservation in allotment of agricultural land, housing, poverty alleviation and various developmental schemes and programs; allotment of land on concessional rate, where such land is to be used for the purpose of promoting housing, shelter, setting up of occupation, business, enterprise, recreation centres and production centres.

Comments: A great relief once implemented.

11. Special provisions for persons with disabilities with high support:- Any person with benchmark disability, who considers himself to be in need of high support, or any person or organisation on his or her behalf, may apply to an authority, to be notified by the appropriate Government, requesting to provide high support.

Comments: This may be helpful to patients who have complications besides thalassemia like cardiac, liver, endocrine complications, bone disease/deformity/ osteopenia or affected with Hepatitis B, C and/or HIV.

- The Chief Commissioner for Persons with Disabilities and the State Commissioners will act as regulatory bodies and **Grievance Redressal** agencies and also **monitor implementation of the Act.**
- District level committees will be constituted by the State Governments to address local concerns of PwDs. Details of their constitution and the functions of such committees

would be prescribed by the State Governments in the rules.

- National and State Fund will be created to provide financial support to the persons with disabilities.

Penalties for offences

- The Act provides for penalties for offences committed against persons with disabilities and also violation of the provisions of the new law.
- Any person who violates provisions of the Act, or any rule or regulation made under it, shall be punishable with **imprisonment up to six months and/ or a fine of Rs 10,000, or both.** For any subsequent violation, **imprisonment of up to two years and/or a fine of Rs 50,000 to Rs five lakh** can be awarded.
- **Whoever intentionally insults or intimidates a person with disability, or sexually exploits a woman or child with disability, shall be punishable with imprisonment between six months to five years and fine.**
- **Special Courts will be designated in each district to handle cases concerning violation of rights of PwDs.**

Dark side of this Act-

Benefits not available for Thalassemia, Sickle Cell Disease and Hemophilia

Job Reservation in Govt. Employment: - As per provisions of RPWD Act 2016, above category of persons with disability have not been given the benefit of Job Reservation in Govt. Employment.

Comments: We have to fight for this.

“YOU HAVE TO FIGHT TO REACH YOUR DREAM YOU HAVE TO SACRIFICE AND WORK HARD FOR IT”

Lionel Messi

आपके लिए इसका मतलब क्या है

“दिव्यांगजन अधिकार अधिनियम 2016” (2016 का सं। 49) संसद में 16.12.2016 को पारित किया गया और 27 दिसंबर, 2016 को राष्ट्रपति द्वारा अधिसूचित किया गया। मौजूदा 7 से दिव्यांगों के प्रकार को 21 तक बढ़ा दिया गया है और केंद्र सरकार को और अधिक प्रकार के दिव्यांगों को जोड़ने का V f/d k j होगा। इस अधिनियम में दिव्यांगों की सूची में थैलेसीमिया, हीमोफिलिया और सिकल सेल रोग शामिल किया गया है।

15 जून, 2017 को सामाजिक न्याय और सशक्तिकरण मंत्रालय के दिव्यांगजन व्यक्ति सशक्तिकरण विभाग द्वारा नियमों को अधिसूचित किया गया।

थैलेसीमिया और अन्य रक्त विकारों के समक्ष इस की मुख्य विशेषताएं

- जो व्यक्ति कम से कम 40 प्रतिशत दिव्यांगता से ग्रस्त हैं उनको “बैंचमार्क दिव्यांग” होने के लिए प्रमाणित किया गया है।

यद्यपि थैलेसीमिया और अन्य रक्त विकारों को अपंगता के प्रतिशत के साथ दिव्यांगता प्रमाण पत्र जारी करने के लिए दिशानिर्देशों को सूचित नहीं किया गया है, लेकिन सुप्रीम कोर्ट के फैसले (<http://thalassemiaindia.org/PDFBook/1311092017040121.pdf>) ने स्पष्ट रूप से “बैंचमार्क विकलांगता” के तहत थैलेसीमिया मेजर को माना है।

दिव्यांगता का प्रमाणपत्र कैसे प्राप्त करें (आरपीडब्ल्यूडी अधिनियम 2016 का अध्याय VII)

दिव्यांगता प्रमाणपत्र के लिए आवेदन—

(1) निर्दिष्ट दिव्यांगता के साथ कोई भी व्यक्ति दिव्यांगता प्रमाण पत्र प्राप्त करने के लिए फॉर्म -IV (इस बुलेटिन में मुद्रित प्रारूप) में आवेदन कर सकता है।

(ए) आवेदन में वर्णित निवास के प्रमाण के साथ आवेदक के जिले में प्रमाण पत्र जारी करने के लिए अधिकृत चिकित्सा प्राधिकरण या किसी अन्य अधिसूचित सक्षम प्राधिकारी;

(बी) या सरकारी अस्पताल में संबंधित चिकित्सा प्राधिकरण जहां वह अपनी दिव्यांगता के संबंध में इलाज करा रहा हो, जमा कर सकता है—

यदि दिव्यांगता वाला व्यक्ति नाबालिग है तो उसकी ओर से आवेदन उसके माता-पिता / अभिभावक द्वारा किया जा सकता है। आवेदन के साथ निम्न भी संलग्न करने हैं—

(ए) निवास का प्रमाण;

(बी) दो नए पासपोर्ट आकार की तस्वीरें; तथा

(सी) आधार नंबर या आधार नामांकन संख्या, यदि कोई हो

ध्यान दें - जिस आवेदक के पास आधार या आधार नामांकन संख्या है उससे निवास का कोई अन्य प्रमाण नहीं मांगा जायेगा।

1. दिव्यांगता प्रमाण पत्र जारी करना - (1) आवेदन प्राप्त होने पर, चिकित्सा प्राधिकारी, आवेदक द्वारा प्रदान की गई जानकारी को सत्यापित करने के बाद केंद्र सरकार द्वारा जारी प्रासंगिक दिशानिर्देशों के अनुसार दिव्यांगता का आकलन करेगा और स्वयं को संतुष्ट करने के बाद कि आवेदक विकलांग व्यक्ति है, थैलेसीमिया हीमोफिलिया और सिकल सेल रोगों के मामलों में फार्म VII (इस बुलेटिन में मुद्रित प्रारूप) में दिव्यांगता का प्रमाण पत्र जारी करेगा।

चूंकि इस बुलेटिन के प्रकाशन तक थैलेसीमिया के प्रमाण पत्र जारी करने के लिए प्रतिशत दिव्यांगता में दिशानिर्देश सरकार द्वारा अधिसूचित नहीं किए गए हैं, अतः आप सुप्रीम कोर्ट के आदेश की प्रतिलिपि दिखाकर अपने रक्ताधान केंद्र से दिव्यांगता प्रमाण पत्र के लिए निवेदन कर सकते हैं सुप्रीम कोर्ट के इस आदेश में थैलेसीमिया की पहचान “बैंचमार्क दिव्यांगता” के रूप में की है

(http://supremecourt.gov.in/supremecourt/2017/22694/22694_2017_Order_11-Aug-2017.pdf) अगर आप निजी अस्पताल से रक्ताधान करा रहे हैं तो उसे जिला अस्पताल / सीएमओ से i f g L K j करना होगा।

(2) चिकित्सा प्राधिकारी आवेदन प्राप्त होने की तिथि से एक माह के भीतर दिव्यांगता प्रमाण पत्र जारी करेगा।

(3) यदि कोई आवेदक दिव्यांगता प्रमाण पत्र जारी करने के लिए अयोग्य पाया जाता है, तो चिकित्सा प्राधिकारी आवेदन पत्र प्राप्त होने की तारीख से एक महीने की अवधि के भीतर फॉर्म 8

के तहत लिखित रूप में उसे बताएगा।

2. जिस व्यक्ति को यह प्रमाण पत्र जारी कर दिया गया है वह सरकार द्वारा उद्धोषित सरकारी और गैर-सरकारी संगठनों की योजनाओं के अंतर्गत दिव्यांग लोगों के लिए स्वीकार्य सुविधाएं, रियायतें और लाभ के लिए आवेदन करने का हकदार होगा।

“बैंचमार्क दिव्यांगता” के तहत सभी व्यक्तियों को उपलब्ध लाभ

1. रोजगार-समान अवसर और गैर-भेदभाव:- उपयुक्त सरकार यह सुनिश्चित करेगी कि, दिव्यांग व्यक्ति, समानता का अधिकार, गरिमा के साथ जीवन और उसको दूसरों के समान आदर, का आनंद प्राप्त हो। कोई भी सरकार रोजगार से सम्बंधित किसी भी मामले में किसी भी दिव्यांग व्यक्ति के साथ कोई भी भेदभाव नहीं करेगी। किसी व्यक्ति की केवल दिव्यांगता के आधार पर कोई पदोन्नति नहीं रोकी जाएगी।

टिपण्णी: अब थैलेसीमिक्स को रोजगार से सम्बंधित समस्याओं का सामना नहीं करना पड़ेगा जोकि हमें डॉ अंजली सरदाना या श्रीमान सुखसोहित सिंह (आई ए एस) के मामले में सामना करना पड़ था।

2. निजी क्षेत्र में नियोक्ताओं के लिए प्रोत्साहन:- सरकार और स्थानीय प्राधिकारी, अपनी आर्थिक क्षमता और विकास की सीमा के भीतर, निजी क्षेत्र में नियोक्ताओं को अपने कम से कम 5% कार्यकर्ता बैंचमार्क दिव्यांगता वाले नियुक्त करने पर प्रोत्साहन प्रदान करने के लिए सुनिश्चित करें।

टिपण्णी: हालांकि हमारे पास नौकरियों में आरक्षण का विशेषाधिकार नहीं है, लेकिन फिर भी इस अधिनियम में यह प्रावधान निजी नियोक्ताओं को थैलेसीमिक्स को नियुक्त करने के लिए प्रोत्साहित करेगा क्योंकि वे “बैंचमार्क दिव्यांगता” के अंतर्गत आते हैं।

3. शिक्षा:- सरकार और स्थानीय अधिकारियों को यह सुनिश्चित करना होगा कि हर बच्चे को जो “बैंचमार्क दिव्यांगता” के अंतर्गत आता है उसके पास उपयुक्त वातावरण में अठारह साल की उम्र तक मुफ्त शिक्षा की सुविधा हो। उन्हें भेदभाव के बिना प्रवेश करें तथा शिक्षा और खेल के सुअवसर और मनोरंजन गतिविधियों के अवसरों को दूसरों के साथ समान रूप से प्रदान करें।

टिपण्णी: अक्षम लोग शिक्षा को देर से शुरू करते हैं और एक कक्षा में 1 वर्ष से अधिक का समय लग सकता है, इसलिए 18 साल की उम्र तक भी बुनियादी शिक्षा पूरी नहीं कर पाएंगे। इसके अतिरिक्त उच्च शिक्षा के दौरान, खर्च भी बहुत अधिक होता है। यह वह समय है जब दिव्यांग लोगों को अधिक वित्तीय सहायता की आवश्यकता होती है अतः मुफ्त और अनिवार्य शिक्षा के अधिकार को 30 साल तक बढ़ाया जाना चाहिए। सभी प्रकार की दिव्यांग संस्थाओं को इसके लिए लड़ना होगा।

4. n f p शिक्षा संस्थानों में आरक्षण:- सभी सरकारी व सरकार से सहायता प्राप्त उच्च शिक्षा संस्थानों को “बैंचमार्क दिव्यांग” लोगों के लिए कम से कम पांच प्रतिशत सीटें आरक्षित करनी पड़ेगी। बैंचमार्क दिव्यांग लोगों को उच्च शिक्षा के संस्थानों में प्रवेश के लिए पांच वर्ष की आयु में छूट दी जाएगी।

टिपण्णी: हमारे दिव्यांगता वर्ग के लिए प्रमुख रूप से एक तात्कालिक लाभ यह हुआ है कि, दो थैलेसीमिक्स को दिल्ली विश्वविद्यालय में प्रवेश मिला और एक थैलासेमिक ने छत्तीसगढ़ में माननीय उच्चतम न्यायालय के आदेश के माध्यम से एम् बी बी एस में प्रवेश प्राप्त किया, दिल्ली में एक अन्य थैलासेमिक ने दिल्ली के माननीय उच्च न्यायालय के जरिए आईपी विश्वविद्यालय में प्रवेश के लिए आदेश प्राप्त किए।

5. सामाजिक सुरक्षा:- सरकार अपनी आर्थिक क्षमता की सीमा के भीतर स्वतंत्र रूप से या समुदाय में रहने के लिए सक्षम होने के लिए पर्याप्त स्तरीय जीवन जीने के लिए आवश्यक योजनायें और कार्यक्रम तैयार करेगी। ऐसी योजनाओं और कार्यक्रमों के तहत दिव्यांग व्यक्तियों को सहायता की मात्रा दूसरों पर लागू होने वाली समान योजनाओं की तुलना में कम से कम 25% अधिक होगी।

दिव्यांग व्यक्तियों के लिए दिव्यांगता पेंशन अधिसूचित आय सीमा के अधीन सुनिश्चित हो। दो वर्ष से अधिक विशेष रोजगार विनियम के अंतर्गत पंजीकृत दिव्यांगों के लिए, किसी भी लाभकारी व्यवसाय में स्थान नहीं प्राप्त कर सकने पर, बेरोजगारी भत्ते की व्यवस्था। उच्च समर्थन

की जरूरतों के साथ दिव्यांग लोगों को देखभाल करने वाले व्यक्ति को भत्ता।

विकलांग व्यक्तियों जो कर्मचारी राज्य बीमा योजनाओं, या कोई अन्य वैधानिक या सरकारी प्रायोजित बीमा योजनाओं के तहत कवर नहीं हैं उनके लिए व्यापक बीमा योजना

टिपण्णी: इससे इस श्रेणी के दिव्यांग लोगों के जीवन को थोड़ा सुविधाजनक बनाया जा सकेगा। हालांकि हमें इस प्रावधान से कैसे थैलेसीमिक्स को लाभ हो सकता है, इसको अध्ययन भी करना है और इसपर काम भी करना है

6. स्वास्थ्य:- अधिसूचित आय सीमा के अंतर्गत दिव्यांग व्यक्तियों के लिए यंत्र और उपकरणों, चिकित्सा और नैदानिक सेवाएं और निःशुल्क शल्य चिकित्सा का प्रावधान। उपस्थिति और उपचार में प्राथमिकता। जीवन रक्षा के लिए आपातकालीन उपचार और प्रक्रियाओं के लिए आवश्यक चिकित्सा सुविधाएं

टिपण्णी: यह प्रावधान मुफ्त रक्ताधान और चिलेशन प्राप्त करने में बहुत मददगार होगा, जिसमें इन्फ्यूजन पंप और स्कैल्प शिरा सेट, साथ ही स्प्लेनेक्टोमी और अस्थि मज्जा प्रत्यारोपण शामिल होंगे। हालांकि आय की अधिकतम सीमा एक मुद्दा हो सकती है लेकिन फिर भी भले ही आय की ऊपरी सीमा 5 लाख रुपये (जैसा कि एमओएचएफडब्ल्यू-कोल इंडिया सीएसआर परियोजना के मामले में) हो कई परिवारों को लाभ होगा। दिव्यांग व्यक्तियों के लिए कोई कतार या अलग कतार नहीं होना चाहिए। हृदय और जिगर आपातकाल चिकित्सा के लिए बेहतर उपचार की अपेक्षा करें

7. ऋण:- लघु ऋण सहित रियायती दरों पर ऋण

टिपण्णी: यह प्रावधान किसी भी गारंटी, रोजगार या सत्यापन क्रेडिट इतिहास के बिना छोटे ऋण पाने में बहुत सहायक होगा।

8. रोकथाम:- सरकार दिव्यांगता को कम करने के उपाय और स्वास्थ्य सेवा को बढ़ावा देने और दिव्यांगता की घटनाओं को रोकने के लिए योजनाएं या कार्यक्रमों को बनायेगी, "जोखिम वाले मामलों" की पहचान करने के उद्देश्य से एक वर्ष में एक बार कम से कम सभी बच्चों को स्क्रीन करें।

टिपण्णी: इस प्रावधान के तहत सरकार को प्राथमिक स्वास्थ्य केंद्रों पर कर्मचारियों को प्रशिक्षण, स्कूलों, स्वास्थ्य सेवा कार्यकर्ताओं, आंगनवाड़ी कार्यकर्ताओं, गांव स्तर के श्रमिकों, रेडियो, प्रेस और इलेक्ट्रॉनिक मीडिया सहित सभी स्तरों पर जागरूकता पैदा करने के लिए पर्याप्त उपाय करने होंगे; थैलेसीमिया की रोकथाम और नियंत्रण के लिए जन्मपूर्व नैदानिक सुविधाओं के विकास के लिए उपाय करेगी।

9. बीमा और पुनर्वास:- सरकार अपने दिव्यांग कर्मचारियों के लिए बीमा योजना बनाये। सरकार और स्थानीय प्राधिकरण, पुनर्वास के कार्यक्रमों के लिए गैर-सरकारी संगठनों को वित्तीय सहायता दे सकती है, विशेष रूप से दिव्यांग व्यक्तियों के लिए स्वास्थ्य, शिक्षा और रोजगार के क्षेत्रों में। पुनर्वास नीति तैयार करते समय सरकार दिव्यांग व्यक्तियों के लिए काम कर रहे गैर-सरकारी संगठनों से परामर्श करेगी।

टिपण्णी: हमें सरकार से इस श्रेणी (रक्त विकार) के तहत दिव्यांग व्यक्तियों को कि किसी भी सरकारी या अर्ध-सरकारी संगठन के कर्मचारी नहीं हैं, के लिए बीमा योजनाएं बनाने के लिए कहना पड़ेगा।

दिव्यांगता (थैलेसीमिया) के क्षेत्र में काम कर रही संस्थाएँ, नीतियों को बनाने और उनके क्रियान्वयन में मजबूत हो जाएँगी।

10. विशेष योजनाएं और विकास कार्यक्रम:- सरकार, “बैंचमार्क दिव्यांगता” वाले व्यक्तियों के पक्ष में योजनाएं बनाने, जैसे कृषि भूमि, आवास, गरीबी उन्मूलन और विभिन्न विकास योजनाओं और कार्यक्रमों के आवंटन में 5% आरक्षण प्रदान करेगी; रियायती दर पर भूमि का आवंटन, जहां ऐसी भूमि का इस्तेमाल आवास, आश्रय, व्यवसाय स्थापित करने, व्यापार, उद्यम, मनोरंजन केंद्रों और उत्पादन केंद्रों के प्रचार के उद्देश्य के लिए किया जाता है।

टिपण्णी: एक महान राहत यदि कार्यान्वित हो जाय

11. अधिक मदद की आवश्यकता वाले दिव्यांग व्यक्तियों के लिए विशेष प्रावधान:- बैंचमार्क दिव्यांगता के साथ कोई भी व्यक्ति, जिसको अधिक मदद की आवश्यकता है, वह स्वयं या किसी

व्यक्ति या संगठन की ओर से, उच्च समर्थन प्रदान करने का अनुरोध करने के लिए उचित अधिकार द्वारा अधिसूचित होने वाली प्राधिकरण को आवेदन कर सकता है।

टिपण्णी: यह उन रोगियों के लिए विशेष सहायक हो सकता है जिनको थैलेसीमिया के अतिरिक्त हृदय, यकृत, एंडोक्राइन जटिलताएं, हड्डी रोग/विकृति, ऑस्टियोपिनिया या हेपेटाइटिस बी, सी और/या एचआईवी जैसी जटिलताएं हैं।

दिव्यांग व्यक्तियों के लिए नियुक्त मुख्य आयुक्त और राज्य आयुक्तों नियामक निकायों और शिकायत निवारण एजेंसियों के रूप में कार्य करेंगे और अधिनियम के कार्यान्वयन की निगरानी भी करेंगे।

दिव्यांग व्यक्तियों के स्थानीय चिंताओं को संबोधित करने के लिए राज्य सरकारों द्वारा जिला स्तर समितियों का गठन किया जाएगा। उनके संविधान का विवरण और ऐसी समितियों के कार्यों को राज्य सरकारों द्वारा नियमों में निर्धारित किया जाएगा।

दिव्यांग व्यक्तियों को वित्तीय सहायता प्रदान करने के लिए राष्ट्रीय और राज्य निधि का निर्माण किया जाएगा।

अपराधों के लिए दंड

इस अधिनियम में दिव्यांग व्यक्तियों के लिए किए गए अपराधों के लिए दंड का प्रावधान किया गया है और नए कानून के प्रावधानों का उल्लंघन का भी उल्लेख किया गया है।

कोई भी व्यक्ति जो अधिनियम के प्रावधानों या उसके अधीन किसी भी नियम या विनियम, का उल्लंघन करता है, तो उसको छह महीने तक कारावास और/या 10,000 रुपये का जुर्माना या दोनों दंडनीय होगा। किसी भी बाद के उल्लंघन के लिए, दो साल तक की कारावास और/या 50,000 रुपये से पांच लाख रुपये का जुर्माना दिया जा सकता है।

जो कोई व्यक्ति विकलांग व्यक्ति को जानबूझकर अपमानित करता है या धमकाता है, या किसी दिव्यांग महिला या बच्चे का यौन शोषण करता है, तो वह छह महीने से पांच साल के बीच कारावास और दंड के साथ दंडनीय होगा। विकलांग व्यक्तियों के अधिकारों के उल्लंघन से संबंधित मामलों को संभालने के लिए प्रत्येक जिले में विशेष न्यायालयों को नामित किया जाएगा।

इस अधिनियम का अंधकारपूर्ण पक्ष -

थैलेसीमिया और अन्य रक्त विकारों में निम्न लाभ उपलब्ध नहीं हैं

सरकारी नौकरी में रोजगार आरक्षण :- दिव्यांगता अधिनियम 2016 के प्रावधानों के अनुसार थैलेसीमिया और अन्य रक्त विकार विकलांग व्यक्तियों की श्रेणी को सरकारी नौकरी में आरक्षण का लाभ नहीं दिया गया है।

टिपण्णी: हमें इसके लिए और अधिक प्रयास करना होगा

“कामयाब होने के लिए अकेले ही आगे बढ़ना पड़ता है,

लोग तो पीछे तब आते हैं जब हम कामयाब होने लगते हैं।”

Form – IV

APPLICATION FOR OBTAINING DISABILITY CERTIFICATE BY PERSONS WITH DISABILITIES

[See rule 18 (1)]

1. Name.....
(Surname) (First name) (Middle name)
2. Father's name.....
Mother's name.....
3. Date of Birth...../...../.....
(Date) (Month) (Year)
4. Age at the time of application:.....Years
5. Sex: Male/Female
6. Address:
(a) Permanent address:
.....
(b) Current address (i.e. for communication).....
.....
(c) Period since when residing at current address.....
7. Educational Status (Pl. tick as applicable)
(I) Post Graduate
(II) Graduate
(III) Diploma
(IV) Higher Secondary
(V) High School
(VII) Primary
(VIII) Illiterate
8. Occupation.....
9. Identification marks
(i).....
(ii).....
10. Nature of disability: Locomotor/hearing/visual/mental/others.....
11. Period since when disabled: From Birth/Since year
12. (i) Did you ever apply for issue of a disability certificate in the past- YES/NO
(ii) If yes, details:
(a) Authority to whom and district in which applied.....
(b) Result of application.....
13. Have you ever been issued a disability certificate in the past? If yes, please enclose a true copy.

Declaration: I hereby declare that all particulars stated above are true to the best my knowledge and belief, and no material information has been concealed or misstated. I further, state that if any inaccuracy is detected in the application, I shall be liable to forfeiture of any benefits derived and action as per law.

.....
(Signature or left thumb impression of person with disability, or his/her legal guardian in case of person with mental retardation, autism, cerebral palsy and multiple disabilities)

Date:

Place:

Enclosure:

1. Proof of residence (Please tick as applicable)
 - (a) AADHAR card
 - (b) Ration card
 - (c) Voter identity card
 - (d) Driving license
 - (e) Bank passbook
 - (f) PAN card
 - (g) Passport
 - (h) Telephone, electricity, water and any other utility bill indicating the address of the applicant
 - (i) A certificate of residence issued by a Panchayat, municipality, cantonment board, any gazette officer, or the concerned Patwari or Head Master of a Govt. School
 - (j) In a case of an inmate of a residential institution for persons with disabilities, destitute, mentally ill, etc., a certificate of residence from the head of such institution.
2. Two recent passport size photographs

(For office only)

Date:

Place:

Signature of issuing authority
Stamp

Download Form

<http://thalassemiaindia.org/PDFBook/1311092017040038.PDF>

As per original notification.
Courtesy NTWS & YTA

Form – VII
Certificate of Disability

(In cases other than those mentioned in Forms V and VI)
(NAME ADDRESS OF THE MEDICAL AUTHORITY ISSUING THE CERTIFICATE)

[See rule 18 (1)]



Certificate No.

Date:

This is to certify that I have carefully examined Shri/Smt/Kum.....

Son/Wife/Daughter of Shri.....

Date of Birth..... Age.....Years,
(DD / MM / YY)

Male/Female.....

Registration No.

Permanent resident of Housing No.

Ward/Village/Street.....Post office.....

District.....state.....

1. Whose photograph is affixed above, and am satisfied that he/she is a case of.....
.....disability

Has been evaluated as per guidelines (to be specified) and is shown against the relevant disability in the table below:-

S. No.	Disability	Affected part of Body	Diagnosis	Permanent physical impairment/mental disability (in %)
1.	Locomotor disability			
2.	Leprosy cured person			
3.	Cerebral palsy			
4.	Dwarfism			
5.	Muscular dystrophy			
6.	Acid attack victims			
7.	Blindness			
8.	Low vision			
9.	Deaf			
10.	Hard of hearing			
11.	Speech and language disability			

12 Disability Certificate Form

12.	Intellectual disability (includes mental retardation)			
13.	Specific learning disabilities			
14.	Autism spectrum disorder			
15.	Mental Illness			
16.	Chronic neurological conditions			
17.	Multiple sclerosis			
18.	Parkinson's disease			
19.	Hemophilia			
20.	Thalassemia			Benchmark Disability
21.	Sickle Cell disease			
22.	Multiple disabilities			

(Please strike out the disabilities which are not applicable.)

2. The above condition is progressive/non-progressive/likely to improve/not likely to improve.

3. Reassessment of disability is:

(i) not necessary,

Or

(ii) is recommended/after.....year.....months, and therefore this certificate shall be valid till.....

(DD / MM / YY)

4. The applicant has submitted the following document as proof of-residence:-

Nature of Document	Date of issue	Details of authority issuing certificate

(Authorized Signatory of notified Medical Authority)
(Name and Seal)

Counter signed

{Counter signature and seal of the Chief Medical Officer/Medical Superintendent/Head of Government Hospital,
In case the certificate is issued by a medical authority who is not government Servant (with seal)}

Signature/Thumb impression of the person, in whose,
favour disability certificate is issued.

"Note: In case this certificate is issued by a medical authority who is not a government servant, it shall be valid only if counter signed by the Chief Medical Officer of the District".

Note: The principal rules were published in the Gazette of India vide notification number S.O. 908 (E), dated the 31st December, 1996.

Download Form

<http://thalassemiaindia.org/PDFBook/1311092017040053.PDF>

As per original notification.
Courtesy NTWS & YTA

To mark the closing of Silver Jubilee Year of National Thalassemia Welfare Society, **8th National Thalassemia Conference** was organized at AIIMS on 17th and 18th December 2016. Around 200 Doctors and 1200 Thalassemia Patients/ Parents participated in the conference. The function was inaugurated by Sh. Hansraj Ahir Hon'ble Minister of State Home Affairs, Govt. of India. Shri Satyendra Jain Hon'ble Minister of Health Govt. of Delhi was the Guest of Honor. Shri Jarnail Singh MLA Tilak Nagar also graced the occasion. Shri Hansraj Ahir Hon'ble Minister of State for Home Affairs the Hon'ble Chief Guest of the Conference congratulated the Thalassemics for passing of Disability Act 2016 which include Thalassemia, Sickle cell disease and Hemophilia in the list of Disabilities.

Thalassemia International Federation (TIF) medical advisor Dr Michael Angastiniotis specially came from Cyprus to organize Patient Capacity Building Workshop on Saturday 17th December 2016. The Patient Capacity Building Workshop was dedicated to motivate and strengthen the voice of Indian Thalassemics to live a quality life with self-esteem and dignity.

Km Surrender Saini, President NTWS while addressing the conference said Thalassemia is a crippling disorder, even with best possible care it becomes difficult for a Thalassemia patient to compete with the peers, high cost of the treatment also ruins the financial status of the families. We have been struggling for long to include Thalassemia in the list of Disability for the purpose of Persons with Disability Act. She informed the Government has passed the bill in both the houses which includes Thalassemia in the list of Disabilities. She specially thanked the Parliament for passing the "Rights of Person with Disabilities Bill" on 16th December on the eve of our 8th NTC 2016. This Bill will help in improving the quality of life of Thalassemics.

Awards given: During every conference NTWS gives two awards. One is scientific award in the honor of renowned paediatrician of Jaipur Dr. B N Dara and the other is Best Social worker award. The Dr. B N Dara award was awarded to Dr Sujata Sinha Consultant, Laboratory Services-RBSK and Adjunct Associate Professor Centre for Comparative Genomics, Murdoch University, Australia. The Best Social worker award was received by Mr. Vinay Shetty Vice President, Think Foundation. Mr. S S Khattar former Secretary TCWA Chandigarh was given Certificate of appreciation for his outstanding help towards the treatment of poor Thalassemics. Mrs. Sreelata Rudra was master of ceremony of inauguration function.

Dr. VP Choudhry gave the lecture on 'Struggling with haemoglobin level'. He mentioned why haemoglobin level falls in spite of regular transfusion and how to overcome this problems. Dr. Rahul Naithani said that there should be no hurry for splenectomy, if at all it has to be done prior vaccination with HiB, meningococcal and pneumonia is must. Post-surgery penicillin prophylaxis is necessary for life long. Dr. Sameer Sood from Star Imaging informed that he has done more than 800 MRI T2* Iron

studies to assess iron overload in Thalassemia Patients. The results are reliable and reproducible. Dr. RN Makroo, HoD Blood Bank, Apollo Hospital New Delhi stressed the need of NAT Testing in Donor's Blood to substantially reduce the incidence of transfusion transmitted infections like Hepatitis B, Hepatitis C & HIV in multi transfused Thalassemia patients. Dr. Vikas Kohli Consultant Cardiologist stressed need of adequate iron chelation since early childhood to prevent cardiac complications in adolescence and adulthood. He advocated the need of cardiac monitoring by ECG and Echo from the age of 15 yrs. Dr. Yogesh Chawla Director PGI Chandigarh informed that now Hepatitis C treatment is easy safe and affordable so must be taken by all eligible patients.

Dr. Michel Angastiniotis spoke on Adult Medical Care in Thalassemia. Dr. JS Arora gave an overview of impact on Thalassemia Management and Prevention struggle by NTWS. Dr. Ravindra Kumar Chhabra PHD Genetics (Thalassemia Major Patient) attracted the attention of all the audience with his success story. Mr. Ajay Gandhi, 45 years old Thalassemia Major patient of Indian origin settled in UK married and having two kids involved everybody in his talk and motivated the patients to encounter the problems with brave face and not to be evasive.

Second day patients and parents had very closed interaction with experts on Transfusion & Chelation in the auditorium, BMT in the conference Hall and NTDT in the seminar room. Dr. Sujata Sinha has a rich experience of prevention and control of Thalassemia in Uttarakhand. She shared her 3 years long experience on Thalassemia screening project with the audience. She said she has developed a low cost Thalassemia control module in Uttarakhand which can be replicated in other states also. Dr. Suthat Fuchareon specially flew from Thailand to enlighten us on need of blood transfusion in NTDT when and why?. Dr. Prantar Chakraborty spoke on complications of Thalassemia Intermedia and their quality of life.

A separate patients capacity building workshop was held under the guidance of TIF Medical Director Dr. Michael Angastiniotis in which various topics like Advocacy by Dr. Michel Angastiniotis, CSR programme, Networking and Alliance by Dr. Ratna Devi were covered besides personal experience of working Thalassemia Societies like UKTS by Mr. Ajay Gandhi, Fundraising in UP by Mr. Pravir Arya, Excellent Blood Donation Drive by Mr. Sarabjit Singh Jabalpur, Low Cost Mass Thalassemia Screening by Mr. Thadaram Tolani and Think Foundation experience by Mr. Vinay Shetty. Ms. Sangeeta Wadhwa specially came from Mumbai to manage this workshop.

Culture evening was also organized on 17th Dec 2016 in the Jawaharlal Auditorium, AIIMS. Ayush, Arushi, Lovish & Sarthak displayed their talent. Dr. Mrs. Swarn Anil anchored the program. The program ended with delicious dinner.

FIT General body meeting was held on 2nd day of conference i.e. Sunday 18th Dec 2016. New executive body was elected with consensus.



Dr. Shruti Kakar consultant Paediatrician and Incharge Thalassemia unit DMC Hospital, Ludhiana flavoured the two day conference with her rich experience in Thalassemia and sweet voice. Our star Thalassemics Tanu Verma and Shobri Ghosh assisted her in managing the stage.



Mr. Gagandeep Singh, Mrs. Monisha Gogoi, Mr. Hardeep Dawar, Pintu Gupta, Aman Arora & Nisikant Beura worked hard to make it a great success.

DR B.N DARA AWARD

NTWS has initiated Dr. B N Dara Award to an Indian medical doctor for dedicated work in the field of Thalassemia & Haemoglobinopathies. Award carries a cash prize and a citation along with a memento. Dr. B.N Dara was a leading Pediatrician of Jaipur.

This award has been conferred to

This time this award was being conferred to **Dr Sujata Sinha**



She is Consultant, Laboratory Services-RBSK (Rashtriya Bal Swasthya Karyakram, National Health Mission) & Adjunct Associate Professor, CCG, Murdoch University, Australia

Associated with development of national policy, technical guidelines and implementation framework for hemoglobinopathies program and currently nationwide implementation of the program under National Health Mission Since 2015

As Project Head and Technical Consultant, Action on Birth Defects Project, National Health Mission, Uttarakhand developed and piloted a State level program for care and control of Thalassemia (2012-2015)

As Hematopathologist and President, Varanasi Region Thalassemia Welfare Society and Coordinator, Thalassemia Working Group, initiated work on Thalassemia in community and on public health perspectives 2006-2012

BEST SOCIAL WORKER AWARD

NTWS has also initiated Best Social Worker Award alongwith Dr. B N Dara Award for a person who has been deeply involved for the welfare of Thalassemia & Haemoglobinopathies. Award carries a cash prize and a citation along with a memento.

This award has been conferred to

This time this award was being conferred to **Mr Vinay Shetty.**



- Has organized more than 5000 blood donation camps in the last 15 years.
- Daily blood donation drives for a continuous period of 6 months at Dadar and Andheri stations in 2007, 2008, 2009.
- Member of the Governing Board of the State Blood Transfusion Council.
- Opened 6 new thalassaemia day care centres in Mumbai and Jalna, Aurangabad & Goa Medical College.
- Liaised with Health Minister to make iron chelators available free to thalassaemia patients in Maharashtra under the Rajiv Gandhi Jeevandayi Arogya Yojana.
- Organized more than 1700 Thalassaemia Screening camps in the past 10 years

Top Five Participating States 8th NTC 2016 :

Delhi-447 I Haryana-155 I Uttar Pradesh-97, Jammu & Kashmir-49 I Madhya Pradesh-46

Airtel Delhi Half Marathon 2016

Last year ADHM was held on 20th November 2016. Mr. Gagandeep Singh, Mr. Pintu Gupta and Ms. Augustina Gogoi participated from NTWS the Great Delhi Run, 6 Km. Marathon is a great platform to raise funds. National Thalassemia Welfare Society raised funds to the tune of Rs.13,22,900. This is the highest fund raised by NTWS through ADHM till now. We were proud to have **Mrs. Rachna Bakhru who participated as our Care Champion Gold and raised Rs.2,55,000 for NTWS. She ran 21 Kms, Half Marathon for the Thalassemics.** NTWS is grateful to her for her great support.



NGO Excellence Programme

In 2015 Novartis in collaboration with SPJIMR designed a customized Management Development Program, spread over a period of 12 months for the NGO's of different states of India who are working for care & control of Thalassemia.

The objectives of this program were:

- To strengthen organizational management, governance and leadership of selected NGOs
- To train and mentor key staff in resource mobilization strategy development and management
- To improve the operational environment of NGOs with appropriate strategy and tools for NGOs
- Short term and long term road map creation with clear outlined vision.
- Financial Management & Fund raising.

The program has enlighten us on various issues for smooth working of an NGO, Sustainability Roadmap, Monitoring, Evaluation and Impact Assessment, Preparing long-term detailed sustainability plan for the NGO. **Most importantly this programme helped us a lot in raising funds under CSR in 2016-17 and we could help more patients with free infusion pumps, filters and medicines and for disease**

Charity partners supporting us under CSR

- Jaquar Foundation Ltd. Gurgaon
- Fluor Daniel Gurgaon
- Ciena India Pvt. Ltd. Gurgaon

New Corporates partnering for blood donation

New Corporates have been associated with NTWS for organizing Blood donation Camps for the support of the Thalassemia patients. Bharti Care, Walmart, JLL, Swarovski, Adglobe, BMR, SOIL, DME, FMS, HDFC Sales, Dorset Kaba, Future Generali, Infocom Network, Big Bazar, Grey Orange Robotics, Indigo Corporate office etc. Among these some Corporates are organizing PAN India blood donation Camps in association with NTWS

Communications Pvt. Ltd, New Delhi is regularly organizing Blood donation Camps every after 5-6 months and supporting the Thalassemia patients. Every year on Reliance Employees Day celebrations Thalassemia kids are invited to share their success stories and awards are distributed along with creating awareness on Thalassemia.

Radisson Blu, Dwarka is also regularly organizing Blood donation Camps for the Thalassemia children. Every year Thalassemia kids are invited to enjoy free, five star hotel hospitality on the eve of Merry Christmas. Thalassemia children enjoys the whole day in the Hotel and back home in the evening with lots of prizes and return gifts.

International Thalassemia Day celebrations 8th May 2017

23rd International Thalassemia Day was celebrated at the **Swarna Jayanti Auditorium LHMC Hospital, New Delhi on 6th May 2017.**

CME was inaugurated by Dr. Ajay Khara deputy commissioner community health and immunisation. During his inauguration speech he mentioned that though treatment has improved but prevention is the best option to save future generation from the menace of Thalassemia. Dr. Jagdish Chandra Director Principal LHMC in his address mentioned that Lady Harding Hospital is the first and only centre having separate transfusion unit for adult Thalassemia patients in medicine department.

There was a gathering of 150 patients, parents & 70 Doctors who participated in the ITD function. Dr. Nupur Parakh Assist. Prof. of pediatrics KSH spoke on overview and diagnosis of Thalassemia Major and Dr. Jagdish Chandra, Director Principal LHMC enlightened the audience "Management of Thalassemia" till 18 yrs. of age. Dr. Anju Seth highlighted the endocrine complications in Thalassemia and Dr. Praveen Kumar on liver problems. Dr. Anupam Prakash Prof. of Pediatrics LHMC discussed about cardiac complications arising out of iron overload.

Thalassemics children Ayush, Arushi, Pragya, Simran, Lovish & Sarthak participated in the colorful cultural program. Punjabi Dance Academy's performance stole the hearts of the audience. Children enjoyed dancing on the Bhangra tune. At the end of the day a huge delicious cake was cut by the Thalassemia kids and all the audience enjoyed eating along with other delicacies & cold drinks in the evening.

FREE HCV TREATMENT

Thalassemia patients over the age of 18 years who have unfortunately become anti HCV positive due to repeated blood transfusions were offered FREE HCV RNA diagnosis along with CBC, SGOT & SGPT on 2nd Sunday clinics in the months of May, June, July, August and October 2017. The tests were done at Metropolis Lab. Patients who were found HCV RNA reactive were given FREE Medicines for full three months course. Those who required six months treatment were given six months treatment. 74 samples were tested during the camps and 29 patients were found HCV RNA positive. Three patients who had brought HCV RNA reports from some other labs were also given FREE medicines as per requirement.

NTWS Annual Blood Donation Camp 2017, Vikas Puri

National Thalassemia Welfare Society Organized its annual blood donation Camp at Society office on Sunday 25th June 2017. The camp began at 9 pm and continued up to 3 pm. 85 units of blood were collected by RML blood bank. All the donors were offered a filling breakfast before donation. Our 80 % donation are regular repeat donors who always keep waiting for 3rd Sunday of June, the day of annual blood donation festival. MLAS Ex MLAS and councilors visited and donated blood for noble cause. NTWS organizes around 60 blood donation camp in a year in Delhi and NCR.

HLA Typing

To support the financially weak Thalassemia patients who are eligible for HSCT Coal India and Ministry Of Health & Family Welfare project, NTWS started subsidizing HLA Typing at concessional rates @Rs.3500 patient plus one Donor. Now we have further reduced the charges to Rs. 2500/- only for patients and one sibling donor to help more patients for HLA typing test.

Total 134 samples (60 patients & 74 Donors) have been processed till 31st Oct 2017. 14 patients got matched sibling donor and approval of 9 patients have been received from the authorities.

HLA Camp at Indore



National Thalassemia Welfare Society in association with Thalassemia & Child Welfare Group Indore organized a HLA Typing Camp on 28-05-2017. Buccal Swab samples from 36 Thalassemia patients were taken for HLA Typing by Dr. J.S. Arora and his Team. Dr. Arora also examined the patient and advised treatment. Gifts & snacks were distributed among the children and parents sponsored by Mrs. Archana Goenka, Prachi Lakhani & family. Dr Rajni Bhandari was the force behind the camp.

Roko Thalassemia launched

Mahavir International in association with NTWS & Artemis Hospital launched Thalassemia Awareness & Prevention program on 17th September 2017 at Manav Rachna University Auditorium. It was a great launching programme where a lot of awareness on Thalassemia was generated keeping an aim to eradicate Thalassemia from India making India Thalassemia free. All the Trustee members of Mahavir International were present. Dr. JS Arora, General Secretary, NTWS Dr. Gaurav Kharya Haemato-oncologist from Artemis Hospital, Mr. Vinay Shetty Vice President Think Foundation, Sangeeta Wadhwa, Thalassemia representative from Sadhu Vaswani Thalassemia Charitable Trust, Mumbai were guest speakers.

Odisha



Odisha Thalassemia Care Society in association with Mazumdar Shaw Medical Centre, Bangalore organized a Thalassemia Clinic and Stem Cell Donor's Registration (by Datri World) on 29 May & 30th May 2017. Dr J.S. Arora was invited from Delhi to give a lecture on the Treatment &

Management of Thalassemia. He examined around 90 patients & advised treatment.

Jalandhar visit :



NTWS is association with Thalassemia Welfare Society Jalandhar is organizing regular thalassemia check-up camp every 2-3 months at Civil Hospital, Jalandhar. Around 20-25 patients are given medicines Kelfer and Defrijet FREE OF COST. Funds are arranged by a trust Help Thalassemics, which is managed by Shri. S. S. Khattar and his family. Mr. Khattar has been General Secretary of TCWA (Thalassemic Children Welfare Association, Chandigarh). Last Thalassemia Health Check-up camp was organized on 20-08-2017. Dr. J.S. Arora and his Team visited from Delhi and 60 Thalassemia patients & parents availed free check-up. Free medicine were distributed to 25 patients by Mr. S.S. Khattar.

Hisar CME and Check-up camp



NTWS in association with Thalassemia Welfare Society, Hisar organized a Thalassemia Checkup Camp at Budhla Sant Mandir Rishi Nagar, Hisar on Sunday, 24th September 2017. The camp was inaugurated by CMO Hisar. Dr JS Arora emphasized on the adequate management of Thalassemia, Dr Dinesh Bhurani spoke on the permanent cure for Thalassemia with BMT. In the camp around 90 thalassemic patients were examined and guided by the eminent doctors. Simultaneously a drawing competition was organized for all the thalassemic patients.

After the check up camp a CME on Thalassemia was organized in association with Doctors of IAP Hisar at Double Spoon Restaurant, Hisar. In the CME Dr JS Arora and Dr Dinesh Bhurani highlighted the management of Thalassemia and the advances in treatment of Thalassemia. The CME was followed by scrumptious lunch. Dr JS Arora and Dr Dinesh Bhurani resolved the queries of the participating doctors. In the end each and every doctor was honored with a memento and Thalassemia awareness board. This initiative will further help the doctors to educate the people of Hisar about Thalassemia.

**NTWS distributed 50 Infusion Pumps
FREE OF COST
to the underprivileged Thalassemia patients
in last 2 years.**

NTWS organized 68 blood donation camps in association with Govt. blood banks from July 2016 to October 2017 and collected 5107 units of blood to strengthen supply of blood.

A MEGA BLOOD DONATION CAMP was organised at Fluor Daniel, Gurugram on 10-08-16, collected 780 units of Blood.

List of Some of the camps are given below.

S.No	Date	Venue	Blood Banks
1	01-07-16	Vatika Tower, Gurgaon	DDU
2	02-07-16	Reliance Communications, Delhi	RML
4	05-07-16	Vatika Atrium, Gurgaon	DDU
5	07-07-16	Vatika Bussiness Park, Gurgaon	DDU
6	11-07-16	Vatika Mindscape, Mathura Road	DDU
7	24-07-16	MLA, Mahendra Yadav's Office, Vikas Nagar	RML
8	04-08-16	MDI, Gurgaon	DDU
9	10-08-16	Fluor India, 8 B Building, DLF Gurgaon	RML
10	10-08-16	Fluor India, Infinity Tower, Gurgaon	LHMC
11	10-08-16	Fluor India, 10 A Building, DLF Gurgaon	LNJP
12	11-08-16	Faculty of Management Studies, DU	RML
13	31-08-16	Swarovski, DLF Gurgaon	DDU
14	01-09-16	Jones Lang Lsalle, DLF Gurgaon	DDU
15	29-09-16	BMR Advisors, Gurgaon	Red Cross
16	01-10-16	DME, Noida	DDU
17	07-10-16	Indigo Office, Gurgaon	RML
18	13-10-16	Radisson Blu, Dwarka	DDU
19	06-11-16	Mahashakti Yogpeeth, Paschim Vihar	DDU
20	13-11-16	Robinhood Army, Gurgaon	DDU
21	14-11-16	C' block Gurdwara, Vikaspuri	LHMC
22	26-11-16	Allied Services, Sarita Vihar	DDU
23	16-12-16	Innovsource P. Ltd., Gurgaon	DDU
24	22-12-16	Reliance Communications, Gurgaon	DDU
25	23-12-16	DHFL Pramerica, Gurgaon	RML
26	06-01-2017	Grey Orange, Gurgaon	DDU
27	20-01-2017	Bharti Care, Gurgaon	DDU
28	28-01-2017	SOIL, Gurgaon	DDU
29	08-02-2017	Big Bazar, EDM, Kaushambi	GTB
30	05-03-2017	Fitness Gym, Khirki Extn	DDU
31	06-03-2017	Andaz, Delhi	RML
32	10-03-2017	Bechtel, Gurgaon	DDU
33	19-03-2017	Opp. Metro Hosp. Patel Nagar	DDU
34	22-03-2017	Radisson Blu, Dwarka	RML

S.No	Date	Venue	Blood Banks
35	28-03-2017	Inventive Health, Gurgaon	DDU
36	07-04-17	Future Generali India Insurance, Delhi	RML
37	12-04-2017	Authbridge Research Services, Gurgaon	DDU
38	13-04-2017	Glitz, Rajouri Garden	RML
39	21-04-2017	Haryana Roadways Association, Gurgaon	RML
40	04-05-2017	SRF, Gurgaon	LHMC
41	24-05-2017	Ciena, Gurgaon	RML
42	24-05-2017	Ciena, Gurgaon	LHMC
43	12-06-2017	Vatika Triangle, Gurgaon	DDU
44	13-06-2017	Vatika City Point, Gurgaon	DDU
45	14-06-2017	Vatika First India Place, Gurgaon	DDU
46	14-06-2017	IDFC Bank Ltd, Cannaught Place	LHMC
47	15-06-2017	Vatika Tower, Golf Road	RML
48	16-06-2017	Vatika Atrium, Golf Road	DDU
49	18-06-2017	Subhash Nagar, Near Shiv Murti, Gurgaon	DDU
50	19-06-2017	Value Edge, Noida	RML
51	20-06-2017	Vatika Professional Point, Gurgaon	DDU
52	22-06-2017	Vatika Mindscape, Mathura Road	RML
53	23-06-2017	Nuvoco Vistas Corp, Ltd, Gurgaon	DDU
54	25-06-2017	Arora Polyclinic, Vikaspuri	RML
55	07-07-17	Fluor Daniel, Gurgaon	LHMC
56	07-07-17	Fluor Daniel, Gurgaon	GTB
57	07-07-17	Fluor Daniel, Gurgaon	LNJP
58	08-07-17	Fluor Daniel, Gurgaon	Red Cross
59	08-07-17	Fluor Daniel, Gurgaon	AIIMS
60	08-07-17	Fluor Daniel, Gurgaon	DDU
61	16-07-2017	Kirpal Ashram, Mianwali Colony, Grgn	LHMC
62	23-07-2017	MLA, Mahinder Yadav's Office, Hastal	RML
63	28-07-2017	Luminous India, Gurgaon	RML
64	31-07-2017	Reliance Communications, Gurgaon	RML
65	06-09-17	Police Station, Paschim Vihar	DDU
66	15-09-17	Dorset Kaba, Mahipalpur	AIIMS
67	16-09-17	Surajbhan DAV School, Vasant Vihar	LHMC
68	03-10-17	DME, Noida	AIIMS



Dr. Arora and Shri Hansraj Ahir MoS Ministry of Home Affairs meeting Shri Thawar Chand Gehlot Minister of Social Justice & Empowerment



World Blood Donors Day rally at GTB Hospital, Delhi by NTWS



Dr. J.S. Arora addressing the media World Blood Donors Day Rally



Dr. JS Arora welcoming Chief Guest MLA Sdr. Jarnail Singh at NTWS Blood Donation Camp



Dr. J.S. Arora & his Team taking HLA samples of the patients at Indore



HLA matching Camp organised at Indore



Dr. Jishan Ahmed & Dr. Aditi Baruah from Assam Medical College Thalassemia Ward



Thalassemia Society of Assam, Dibrugarh



Dr. V P Choudhury giving a talk on Thalassemia at Uttarakhand



Jharkhand Thalassemia Society



NTWS organised a series of Blood Donation Camp in association with the Vatika Groups, at Gurgaon



Mr. Gagandeep Singh NTWS Staff Donating Blood on 25th June, 2017 at Arora Polyclinic, Vikas Puri, N.D.



Odisha visit of Dr. J.S. Arora



Thalassemia Check-up Camp, Odisha



Dr. Sunil Bhatt addressing at Cognation 2017, Odisha



Seminar for Thalassemia & Sickle Cell Patients, Nagpur



Thalassemia Check-up Camp, Jalandhar 20th August, 2017



CME on Thalassemia, Hisar 24th September, 2017



Thalassemia Check-up Camp, Hisar



BPPC Kerala observed Patient Solidarity Day

Blood Patients' Protection Council observed Patient Solidarity Day before medical college hospital, Calicut, Kerala, India. To mark the event, a Rally of blood disorder patients, a public meeting in Medical College Town Street and a protest fast was organized. Participants demanded from the Government to take urgent step to implement the recommendation of Human Right commission and also to bring the health care under the purview of human right service. Council also demanded to the government to withdraw the baseless case charged against the parents of Leukemia, Thalassemia patients. Council General Convener, Kareem Karassery Inaugurated the program. Moideen Poovaduka, KK Nizar, Prasidhan AN Lissi. Vahab, Sulu Ashraf, Ummer Ali and Maqsood led the Rally.

TCWA, Chandigarh Report

With the efforts Sh. Rajinder Kalra, General Secretary, TCWA, Regional Director, GMs, AGMs and some other officers of Reserve Bank of India visited Thalassaemia



Ward, APC, PGI on 5th Oct 2017 and donated two computers, one printer, one microwave and medicines worth Rs. 30,000/- for the use of thalassemic patients. Regional Director, RBI also enquired about the health of patients by making personal contact with them and appreciated the efforts of TCWA for helping the patients and maintaining the Thalassaemia Ward. Dr. Deepak Bansal, APC, PGI though having very busy schedule was also present and he briefed the visiting officers regarding thalassaemia disease. The RBI Officers have also ensured that every help will be given to the Association in future also. Sh. Rajinder Kalra, General Secretary and Sh. Arjan Singh, Vice-President thanked the Regional Director and other officers of RBI for this act of kindness.

CME at Nagpur

Indian Medical Association, Nagpur and Thalassemia Sickle Cell Centre, Nagpur jointly organize a Thalassemia & Sickle Cell Patients Seminar on 26-05-2017. Dr. Vinky Rughwani was force behind this seminar.



NATIONAL THALASSEMIA WELFARE SOCIETY (Regd.)

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

www.thalassemiaindia.org, E-mail : ntws2015@gmail.com

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Form can be download from website : www.thalassemiaindia.org

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