FEDERATION OF INDIAN THALASSEMICS

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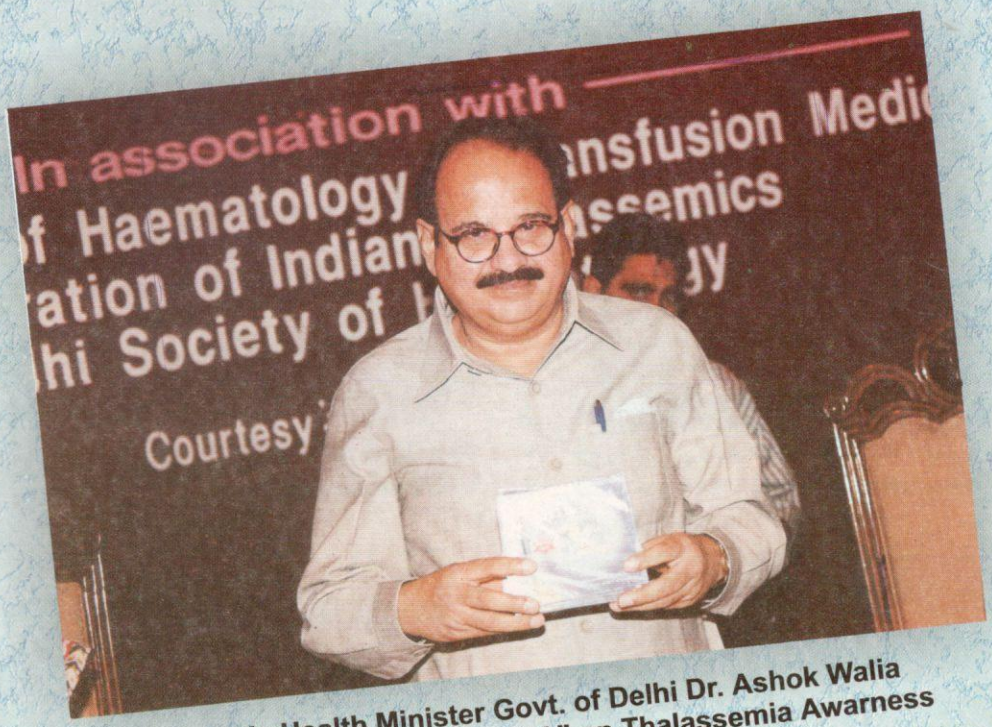
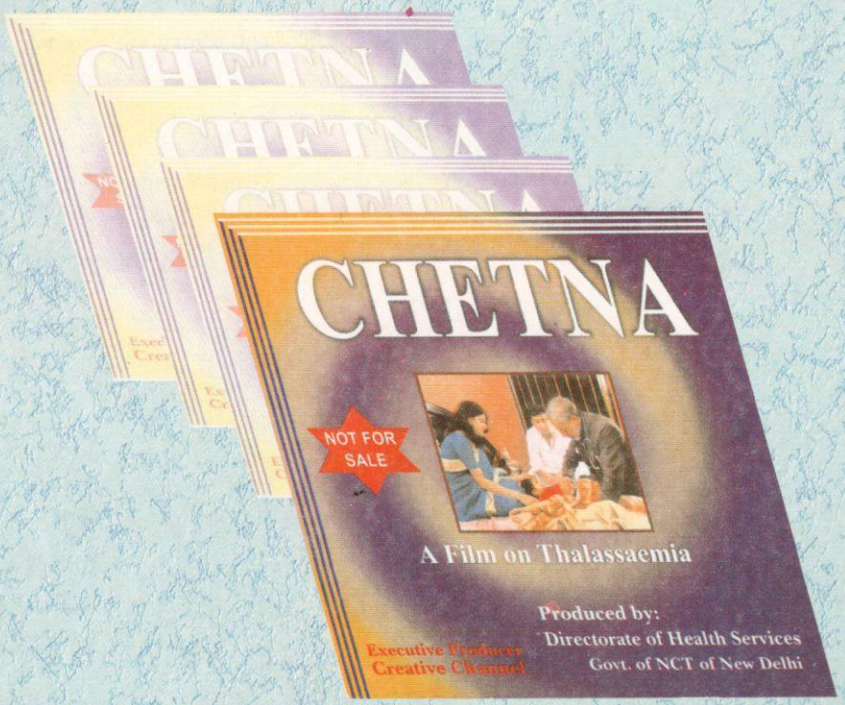


Hon'ble Health Minister Govt. of Delhi Dr. Ashok Walia releasing CD of Flim "CHETNA" on Thalassemia Awarness



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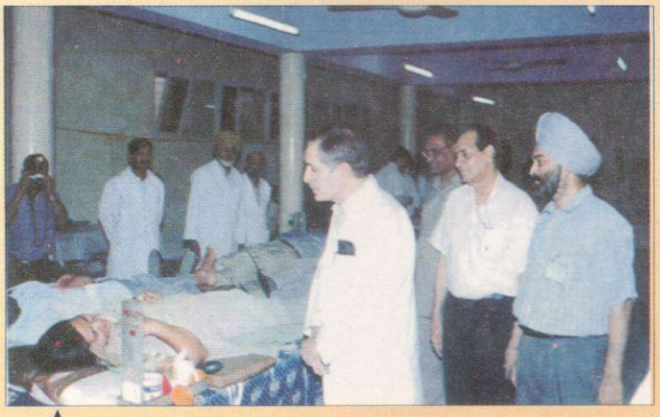
Blood Donation Camps Organised by TCWA, Chandigarh



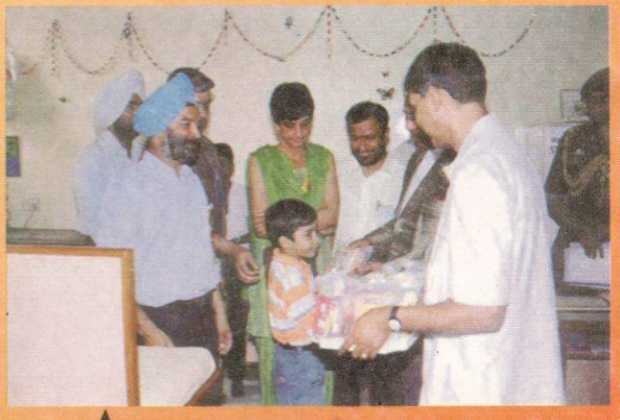
1st Blood Donation Camp

2nd Blood Donation Camp

3rd Blood Donation Camp

4th Blood Donation Camp

5th Blood Donation Camp



6th Blood Donation Camp

Editorial

A few days back, a person came to me and said Dr. Sahib, do you recognize me. However the face was a bit familiar but I could not recognize him. He said, I had a tailoring material shop across your clinic now I have shifted to a place approximately 4-5 kms away.

Then he told me that he has a child who has been just diagnosed Thalassemia Major. I was shocked! He said I had been observing your activities and blood donation camps regularly but never thought this could happen in my own life.

I heard a resident doctor working in the Thalassemia unit of a prestigious hospital when she was unmarried. Later she went abroad, married and delivered a Thalassemia Major child.

Recently a young educated, cute Punjabi pregnant lady came and request me to test, for sex determination of the foetus.

She had already one girl child. I usually charge just Rs. 250/- for ultrasound in pregnancy on charitable basis. She was ready to pay up to Rs. 5000/- for sex determination. She was from a lower middle class family. I asked her instead of going for sex determination, you should go for Thalassemia screening, since it is more important to have a normal healthy child irrespective of male or a female.

I also explained her the problems and the high incidence of Thalassemia in punjabies and and told her the cost of test would be just 1/10th of that you are paying for sex determination i.e. approx. just Rs. 500/-. She said I shall go back and discuss in the family. However if you are ready to offer us sex determination, we have come prepared and are ready to pay.

One of my Punjabi friend who is an ultrasonologist and his wife is a paediatrician. Once I asked him have you got yourself tested for Thalassemia carrier status. He immediately said, I don't require it. We both are healthy, my 1st child is hale and hearty and it is not so common. Why should I go for it? Luckily they delivered a non-Thalassemic child after 2-3 years. When a couple, an ultrasonologist who looks into foetal deformity during pregnancy and a paediatrician who treats the Thalassemic children don't consider it necessary to go for Thalassemia screening, who else will volunteer?

Once one of my junior colleague, an obstritician & gynacologist said, "Sir, you are doing a yeomen job by creating awareness on Thalassemia". I asked her to how many pregnant women have you advised Thalassemia screening? She started saying No one pretext or the other. In the last I had to say that don't flatter me. If you are really concerned about my social objective then please advise Thalassemia screening to each & every pregnant woman whenever she pays her first to you. ? God knows what she is doing.

In a society where such examples are not rare but experienced by all of us very frequently, Thalassemic families should not lose heart and let it happen. They should strive hard and stress again & again to the prospective and young couples to go for Thalassemia screening before conception.

Dr. J.S. Arora

IMPORTANT

Editorial Board of National Thalassemia Bulletin has decided to print directory of Societies and Day Care Centres working in the field of Thalassemia. Kindly send following information immediately:

1. Name, Address, Phone Nos. (Residence, Office, WLL, Cell), Fax and E-mail of Society, President and Secretary.
2. No. of patients. Transfusion Centre, Address, Phone No. and Name of Consultant with Phone No.
3. Blood Bank, Address, Phone No. and Name of Blood Bank Incharge with Phone No.

Assessment of Nutritional Status and Knowledge regarding Iron Rich Foods inThalassemia Patients before and after Intervention

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Introduction

In Thalassemia persistence of foetal haemoglobin in adult life makes RBCs vulnerable to haemolysis prematurely. This is the cause of congenital haemolytic anaemia or Thalassemia.

In India it is estimated that nearly 8000-10000 new Thalassemics are born every year. Beta Thalassemia gene is more commonly found in Sindhis, Punjabis, Bengalis and Gujaratis.

The conventional management of Thalassemics is based on a programme on regular blood transfusions and iron chelation. In such chronic genetic diseases, nutrition is generally neglected and parents of Thalassemics are always confused about the diet of their children.

Aims & Objectives

Present interventional study therefore, was conducted for:

1. assessment of nutritional status of Thalassemics,
2. to observe actual intake of calorie, protein and iron as compared to recommended dietary allowances for the age,
3. to know about their parent's knowledge regarding iron rich foods, low iron diet and other food items,
4. to observe common food fads and common problems of these patients, and
5. to give them proper guidance accordingly for prevention of malnutrition and clearing the doubts of the parents

Materials and Methods

In present interventional study, a total of one hundre (100) patients were selected from Thalassemia day car centre of our hospital and divided into two groups wit fifty (50) patients each. All patients were categorize and divided again according to age groups in 1-3 years 4-6 years, 7-9 years and 10-12 years of age.

Before intervention fifty (50) patient's nutritiona assessment was done. Weight and height of th patients were compared with fiftieth (50th percentile of the NCHS standards. Nutritiona intake (calories, proteins and iron intake) wa calculated by using '24 hours recall method' an 'food frequency' method. Questionnaires were distributed to the patients for knowledge regardin iron rich food and other food habits. After fift patient's assessment all Thalassemia patients were advised about the proper diet and their queries were solved on the spot. After this intervention and time-to-time Interaction with the patients, again fifty Thalassemics were reassessed. Statistical analysis was done by Wilkoxan's method.

Results

Table-I shows that in control group average weight for 1-3 years and 4-6 years age group was less than study group patients, but in 7 -9 years and 10-12 years age group average weight was almost same. All patients were under-weight and height was also less as compared to fiftieth percentile of NCHS standards. Height of patients of control group (1-3 years, 4-6 years and 7-9 years age group) was less than study group patients except in 10-12 years of age group.

Table-2 shows that in the control group, the average calories and protein intake was less than study group

patients and in both the groups, calories and protein intake were less than R.D.A. given by ICMR.

TABLE-1

AGE GROUP	CONTROL GROUP		STUDY GROUP		NCHS STANDARDS	
	Avg. wt. (kg)	Avg. height (cm)	Avg. wt. (kg)	Avg. height (cm)	Avg. wt. (kg)	Avg. height (cm)
1-3 YEARS	10.30 (n=8) 079.50		12.10 (n=6) 093.08		13.67	092.30
4-6 YEARS	14.11 (n=16) 098.83		15.58 (n=16) 104.83		18.80	110.30
7-9 YEARS	20.30 (n=13) 119.84		20.29 (n=11) 122.40		25.38	126.80
10-12 YEARS	26.80 (n=13) 136.10		25.26 (n=17) 127.10		38.81	147.60

TABLE-2

AGE GROUP	CONTROL GROUP		STUDY GROUP		RDA	
	Avg. calories (kcal)	Avg. protein (gm)	Avg. calories (kcal)	Avg. protein (gm)	Avg. calories (kcal)	Avg. protein (gm)
1-3 YEARS	851	19.60	1073	24.00	1240	22
4-6 YEARS	987	17.80	1317	30.80	1690	30
7-9 YEARS	1203	19.90	1578	37.30	1950	41
10-12 YEARS	1470	27.30	1561	40.30	2190	54

TABLE-3

QUESTION NUMBER	CONTROL GROUP		STUDY GROUP	
	CORRECT (PERCENT)	WRONG (PERCENT)	CORRECT (PERCENT)	WRONG (PERCENT)
Q.No. 1	86	14	94	06
Q.No. 2	58	42	64	36
Q.No. 3	68	32	88	12
Q.No. 4	50	50	52	48
Q.No. 5	44	56	76	24
Q.No. 6	86	14	86	14

Table-3 shows that in the control group parents, 86% of the parents had correct knowledge about the diet of Thalassemics but after the intervention, 94% study group parents gave correct answers (Q-1).

Knowledge regarding iron rich foods was assessed by different questions (Q-2,3,4) and it was observed that before intervention 58%, 68% and 50% parents gave correct answers in Q. no. 2, 3 and 4, respectively, but after the intervention 64%, 88% and 59% parents of the study group gave correct answers in Q. nos. 2, 3 and 4, respectively.

It was observed that before intervention, 56% parents had food fads regarding hot and cold foods but after intervention, only 24% parents had food fads in the study group (Q-5).

Knowledge regarding beneficial effects of tea for these patients was also observed and it was noted that in both the groups, 86% parents gave positive answers (Q-6).

Discussion

Results showed good improvement in terms of increased calorie and protein intake and enough knowledge to the parents about iron rich foods and other dietary habits. Growth parameters also improved in some patients. As Table-1 showed that in age group 1-3 years, 4-6 years and 7-9 years average weight and height were increased but it was not statistically significant due to the fact that growth parameters could not be drastically changed in 6 months' time. The growth parameters were not improved in 10-12 years of age group. Another fact about the growth of Thalassemics is that hypoxia is the main cause of growth retardation in these children. As haemoglobin drops within 10-15 days of a blood transfusion, hypoxia occurs. So, with regular blood transfusion and good nutrition, goal of normal growth can be achieved. Regular transfusions are needed for all Thalassemics who cannot maintain haemoglobin above 7 gm/dl. The goal of transfusion therapy is to keep the haemoglobin level at a minimum baseline level. Maintenance of normal haemoglobin level prevents hypoxemia, hypersplenism and promotes normal physical activity and growth.

Table-2 shows improved intake of calories and protein in study group patients (after intervention). The difference between two groups was statistically significant. Befo intervention it was observed that after a monthly blo transfusion these children showed good appetite or after 13-15 days. As soon as the haemoglobin lev dropped gradually, their appetite decreased and the overall monthly nutritional intake was reduced. Son patients also had problem of PICa with low level haemoglobin and at this time they consumed non-nutritio things also. In interventional programme these childr were advised to have such high calorie high protein foo items, which could give concentrated source of calori and proteins in very low quantity of food items. The were advised to avoid unnecessary food fads whi counselling.

Iron intake of all children was also calculated and it wa less in both the groups as compared to recommende allowances of iron. Iron chelation therapy is instituted t take care of iron overload.

Iron intake of all children was calculated. It wa very less in both the groups as compared to RD. of iron. Iron chelation therapy is instituted to tak of iron overload. Parents of Thalassemics know about it and they feel that iron rich foods which ar synonym to nutritious foods should be prohibite for these children. This concept leads to furthe confusion. As a fact that iron deficiency anaemia i the most prevalent problem in the world as well a in India, iron intake of these children is also less With each unit of packed cells transfusion 200-250 mg of iron and by ten years of age about 20-30gm iron gets deposited in various parts of the body With such huge amounts of iron overload from transfusions it can be fatal also. The amount o dietary iron is much less than iron received through blood transfusions, especially in vegetarian diets, where the amount of oxalates and phytates are very high in the diet.

Table3 showed that overall knowledge of the parents improved drastically after intervention. As 86% parents had correct knowledge before intervention that proper diet i.e. normal dict or little low iron diet should be given to their children, but after intervention 94% parents have correct knowledge (in No. 1). Results showed that in assessment of knowledge regarding iron rich foods before intervention, 42%, 32% & 50% parents had incorrect

information but after intervention only 36% & 12% parents had incorrect information in Q 2 & 3 but in Q 3 parents had confusion regarding leafy vegetables and almost same number of parents had given correct answers (52%) as in control group.

In our intervention programme parents and patients were given proper information regarding iron rich foods and advised to have tea along with meals to inhibit iron absorption from gut. Strong tea having tannins reduce iron absorption.

As far as iron is concerned no strict regulations regarding diet can be recommended. However food with rich iron content e.g. meat, liver, kidney, leafyveg, jaggery and dates should not be taken on daily basis and parents should know about these foods.

The conventional treatment modality itself has seen a progressive transformation of Thalassemia major from an invariably fatal disease in to a chronic disease permitting a normal life or at least very prolonged survival.

So we conclude that in such genetic disorders, role of proper nutrition, dietary counselling and proper knowledge along with conventional management of regular blood transfusion and iron chelation is definitely helpful in prevention of malnutrition and growth retardation.

A high calorie, high protein diet along with vitamin "C" rich and calcium rich foods is an ideal diet pattern with correct knowledge about iron rich foods. It should be explained to the parents and patients that iron rich foods are not strictly prohibited at the same time should not be taken daily.

1. No drugs containing iron should be taken.
2. Foods rich in iron should be avoided, e.g. meat, liver, kidney, egg yolk, green vegetables, and jaggery.
3. Food should not be cooked in iron pots.
4. Do not use food preserved/kept in copper utensils. Copper increases iron absorption.
5. Meals should include bread, cereals, milk, moong dal, and soyabean to reduce iron absorption especially from iron rich foods.
6. Citrus fruits (lemon, orange, sweet lime, etc.), guava, amla, tomato, and fruit juices rich in vitamin C should be avoided along with meals.
7. Strong tea/coffee should be drunk at meal times.
8. Milk and milk products should be consumed frequently.
9. Sugars and sweets should not be taken with food. They can be eaten between meals.
10. Take high protein, high calcium diet.

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Benefits of Using Leukocyte Depleting Filters

Thalassemics require only red blood cells while large numbers of donor leukocytes are present in blood components including RBC packed cells. These leukocytes are responsible for several complications associated with blood transfusions e.g.

- NHFTR (Non-haemolytic febrile transfusion reactions)
- Platelet refractoriness
- GVHD (Graft versus host disease)
- Transmission of viruses....CMV, HTLV-1

N.H.F.T.R. is the major complication of transfusing white cells to a patient. It accounts for 70% of total transfusion reactions. They are characterised by flushing of face, fever, chills, sweats, low back pain, difficulty in breathing, palpitation, severe chest pain, nausea, etc. It leads to Blood wastage and increased patient morbidity.

Cause: due to leukocyte antibodies.

The severity of the reaction depends upon the absolute number of leukocytes present in transfused blood. These can be prevented or lessened by transfusing leukocyte depleted blood and blood products.

Alloimmunization to HLA antigen is a major cause of refractoriness to platelets transfusion in multi-transfused patients. This creates problem during B.M.T. Development of HLA antibodies can be reduced up to 50% by leukodepletion.

There is evidence that transmission of Herpes & CMV infections can be reduced by using leukocyte depleting filters (Human Herpes virus and CMV virus is found in leukocytes). There is also evidence that allogenic leukocyte can stimulate HIV-1 replication and secondary dissemination in vitro. It has prompted to consider whether Leukodepleted blood transfusions can impact the clinical course of HIV infected patients.

Studies have shown that immunosuppressive effects associated with blood transfusion can be prevented by leukocyte depletion.

As technology improves use of leukocyte filtered blood components may prove to reduce transfusion transmitted infections also.

Transfusion transmitted reactions can be reduced by transfusing leukodepleted packed cells. Leukodepletion can be done by several methods in the blood bank. It has its own advantages and disadvantages. It is not always feasible due to various reasons. However new technology is in the pipeline where Leukocyte depletion will be done at pre-storage level by the blood banks. **Till such time Thalassemics have the option to use bed side leukocyte depleting filters which can be used at the time of transfusion. However, these do cause extra burden on the pocket of the Thalassemic parents but if we weigh its benefits vis a vis its cost we save lot of complications, wastage of blood and GVHD at the time of BMT.**

श्री हनुमंत फाऊंडेशन सिरसा

श्री हनुमंत फाऊंडेशन सिरसा द्वारा रक्त रोग थैलासीमिया की जांच तथा बचाव में सहायक इलैक्ट्रोफोरेसिस मशीन की स्थापना श्री हनुमंत चैरिटेबल अस्पताल नेहरू पार्क सिरसा में की गई है। यह आधुनिक मशीन आयातित है तथा कम्प्यूटरराईज्ड है। अब तक इस मशीन की सुविधा केवल दिल्ली, चंडीगढ़ आदि जगह पर थी तथा वह भी लगभग 500-600 रुपये प्रति टैस्ट। अब दानी समाज सेवियों के सहयोग से यह मशीन सिरसा में स्थापित हुई है तथा बिना लाभ-हानि के सिद्धांत पर टैस्टिंग फीस केवल 150 रुपये प्रति टैस्ट रखी गई है अत: जरूरत मंदों से अनुरोध है कि इस सुविधा का लाभ उठायें।

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फिल्टर प्रयोग करने के लाभ

थैलासीमिक रोगियों को केवल लाल रक्त कणों की ही आवश्यकता होती है जबकि ब्लड बैंक द्वारा उपलब्ध कराये गये पैक्ड सैल्स में श्वेत रक्त कण भी काफी मात्रा में पाए जाते हैं। ये श्वेत रक्त कण ही रक्त संचारण के समय होने वाले दुष्प्रभाव जैसे कि बुखार, ठंड लगना, कमर दर्द होना, मुँह का लाल होना, सांस लेने में परेशानी होना, छाती में दर्द होना और उल्टी होना इत्यादि के मुख्य कारक होते हैं।

इसके अतिरिक्त रोगी के HLA (Human Leucocyte Antigen) के प्रति कुछ ऐसे प्रतिरोधक अवयव बन जाते हैं जिससे भविष्य में अस्थी-मज्जा प्रत्यारोपण के समय आवांछित प्रभाव उत्पन हो सकते हैं। कुछ संक्रमण जैसे CMV (Cyto Megalovirus) और HTLV-1 (Human T cell Lymphotropic Virus) आदि भी इन्ही श्वेत रक्त कणों द्वारा रोगी के शरीर में संक्रमण फैला सकते हैं।

इन सभी दुष्प्रभावों की तीव्रता रक्त में उपस्थित श्वेत रक्त कणों की मात्रा पर निर्भर करती है।

उपरोक्त सभी दुष्प्रभावों को पैक्ड सैल्स में से श्वेत रक्त कणों को हटा कर समाप्त किया जा सकता है अथवा कम से कम किया जा सकता है। श्वेत रक्त कणों को हटाने के कई उपाय है जोकि ब्लड बैंक द्वारा किये जा सकते हैं। इन सब के अपने अपने फायदे और नुकसान हैं और विभिन्न कारणों से यह हमेशा सम्भव नहीं हो पाता। इन सभी समस्याओं से बचने के लिए रक्त संचारण के समय **Lekocyte Depleting Filter** का प्रयोग सरल व उत्तम है। फिल्टर दो रूप में मिलते हैं, एक यूनिट बल्ड के लिए तथा दो यूनिट बल्ड के लिए। जिनको एक ही समय पर क्रमश: एक अथवा दो यूनिट रक्त संचारण के लिए प्रयोग किया जाता है। यद्यपि इसमें थोड़ा खर्चा अवश्य आता है परन्तु इसके प्रयोग से होने वाले लाभ को देखते हुए यह बहुत महंगा नहीं है।

ऐसा भी सोचा जा रहा है कि संभवत: HIV (Human Immunodeficiency Virus) और Herpes Virus का संक्रमण भी Leukocyte Filter का प्रयोग करके रोका जा सकता है।

थैलासीमिया में आहार

1. थैलासीमिया रोगी में लौह युक्त कोई भी दवा (एलोपैथिक, आर्युवैदिक, युनानी अथवा होम्योपैथिक) का प्रयोग नहीं करना चाहिए।

2. अधिक लौह वाले आहार विशेष रूप से मांसाहारी आहार जैसे जिगर, गुर्दे, बकरे का मांस, अंडे की जर्दी आदि, तथा हरे पत्ते की सब्जियां जैसे पालक, सरसों का साग, मेथी इत्यादि तथा गुड़ का प्रयोग नहीं करना चाहिए।

3. लोहे के बर्तन में पका हुआ खाना नहीं खाना चाहिए।

4. तांबे के बर्तन में रखे हुए खाद्य पदार्थ प्रयोग नहीं करने चाहिए, क्योंकि तांबा लोहे के अवशोषण में सहायक होता है।

5. भोजन के साथ विटामिन-सी युक्त दवा अथवा खाद्य पदार्थ जैसे नींबू, संतरा, मौसमी, आंवला आदि का प्रयोग नहीं करना चाहिए। इन पदार्थो को मुख्य भोजन के दो घंटे के अंतराल से लिया जा सकता है।

6. भोजन में अनाज, दूध, दालें और सोयाबीन आदि का प्रयोग अधिक करना चाहिए। ये पदार्थ भोजन में लोहे के अवशोषण को कम करते हैं।

7. भोजन के साथ चाय अथवा कॉफी का प्रयोग भोजन में उपस्थित लोहे के अवशोषण में अवरोध पैदा करता है।

8. थैलासीमिया मेजर रोगी को दूध तथा दूध के बने हुए पदार्थ जैसे दही, पनीर, छैना आदि अधिक मात्रा में प्रयोग करने चाहिए।

9. चीनी तथा अन्य मीठे पदार्थ भोजन के साथ न लेकर 1-2 घंटे आगे पीछे लेने चाहिए, क्योंकि चीनी आदि मीठे पदार्थ लोहे के अवशोषण में सहायक होते हैं।

10. आहार में प्रोटीन तथा कैल्शियम युक्त पदार्थ जैसे दालें, पनीर आदि का प्रयोग अधिक करना चाहिए।

Thalassemic Children Welfare Association, Chandigarh

Blood Donation Camps organised during this summer seasons from May to August 2003.

1st Blood Donation Camp held on 8-5-2003 in LT-1, PGI, Chandigarh. The camp was inaugurated by Prof. S.K. Sharma, Director, PGI Chandigarh at 9.30 A.M. other Faculty members i.e. Dr. R.K. Marwaha, Dr. Amita Trehan, Dr. Neelam Marwaha of Blood Bank PGI also visited at the time of inauguration. In addition Dr. J.G. Jolly Former Incharge Blood Bank also visited the camp as many as 270 blood donors donated the blood in the camp.

2nd Blood Donation Camp was held on 31-5-2003 in LT-1, PGI Chandigarh. The camp was organised with the association of State Bank of India, MI Branch, PGI Chandigarh it was inaugurated by Chief General Manager Mr. Yogesh Agarwal LHO Chandigarh. He also gave mementos to the blood donors. More than 180 units of blood were donated by the donors. Dr. Neelam Marwaha Head, Deptt. of Blood Bank PGI and his team conducted the camp. Sh. Yogesh Agarwal promised to help the association in organising awareness programmes and donation.

3rd Blood Donation Camp was sponsorship by Chitkara Institute of Engineering & Technology. The inauguration of the camp was done by Dr. Ashok Chitkara & Dr. (Mrs.) Madhu Chitkara at 9.45 a.m. respectively. More than 180 donors donated blood in the camp. A team of blood bank PGI along with Dr. Neelam Marwaha, Head of the Blood Bank PGI conducted the camp. Dr. Ashok Chitkara & Dr. (Mrs.) Madhu Chitkara also visited Thalassemia ward & distributed sweets among the Thalassemics. Shri Chitkara promised to adopt some of Thalassemics.

4th Blood Donation Camp was organised on 21-6-2003 in LT-1 PGI Chandigarh. The camp was inaugurated by Shri J.P. Verma, General Manager SBI, LHO Sec. 17, Chandigarh at 10.00 a.m. He also visited the Thalassemia ward & appreciated the efforts of the Association in providing best facilities to the Thalassemics. He also distributed gift packets amongst the Thalassemics. More than 180 donors donated blood in the camp.

5th Blood Donation Camp was organised by the Association, which was held on 19-7-2003 in Zakir Hall. The camp was inaugurated by Shri Harbhagwan Singh, Advocate General, Punjab High Court at 11.00 A.M. He also gave mementos to some donors. He also visited the Thalassemia ward in APC Building. He was very much impressed to see the arrangements for Thalassemics. He also distributed gifts to the children in the ward. The blood bank Doctors & Technicians conducted this camp under the supervision of Dr. Neelam Marwaha. More than 205 donors donated blood in the camp. Shri Harbhagwan Singh donated Rs. 11,000/- and promised to help in collecting more donation.

6th Blood Donation Camp was held on 2-8-2003 in LT-1 PGI Chandigarh. The camp was inaugurated by Justice O.P. Verma (Retd.) Governor Punjab & Administrator U.T. Chandigarh at 11.00 A.M. and interacted with the blood donors & gave mementos to the blood donors. The President Shri S.P. Ajmani & General Secretary Shri S.S. Khattar welcomed H.E. The Governor Punjab & Administrator U.T. Chandigarh, many faculty members of the PGI were also present. Later on H.E. visited the Thalassemic ward and distributed gift packets to the Thalassemics. A memorandum of demands of the Association was presented to H.E. He assured that the necessary action would be taken on them. In the camp 165 donors donated the blood. The Governor ordered for exemption of Sales Tax on Kelfer & Desferal, which are being used for Thalassemics. The Governor also promised for Awareness Programme in schools & colleges for Blood Screening of Youth for Thalassemia disorder.

Editorial Comment

It is estimated that TCWA, Chandigarh is collecting over 50% of its requirement of blood that too in summer session.

If all Thalassemia societies successfully make this effort no Thalassemic will remain anaemic. It will also help in normal growth and puberty if coupled with adequate iron chelation.

National Thalassemia Welfare Society

BLOOD DONATION CAMPS

1. National Thalassemia Welfare Society organised a Blood Donation Camp at Nij Thaun Gurudwara Baba Budha Sahib, Block-1, Subhash Nagar, New Delhi-110027 on Sunday the 13th July 2003. 26 units of blood were collected by DDU Hospital blood bank team. This camp was preceded by a Lecture on Thalassemia & Blood Donation by Dr J.S. Arora to the congregation during a ceremony at Gurudwara Sahib. Simi and Sd. Baldev Singh helped us in organization of this camp

2. A Blood Donation Camp was organized at Gurudwara Sahib Income Tax Colony, DU-Block Pitampura on 27th July 2003. 36 units of blood were collected by DDU Hospital blood bank team. This camp was also preceded by a Lecture on Thalassemia & Blood Donation by Dr J.S. Arora on the occasion of "Pooranmasi" celebration by Gurudwara Sahib. Simi, Sd. Man Singh, Capt. Narinder Singh and Mr. G.S. Bedi helped us in organization of this camp.

3. National Thalassemia Welfare Society organised a Blood Donation Camp in association with M/s. Orion Dialog Pvt. Ltd, B-134, East of Kailash, New Delhi on Monday, 11th August 2003. 33 units of blood were collected by AIIMS blood bank team. Ms. Tina, Gurpreet, Rajni, Sandeep, Karishma, Nishant and George really worked hard and help us a lot in making all the arrangements.

4. NTWS celebrated 15th August 2003, the Independence Day by organizing blood donation camp at DT Centre, Gurgaon Mehrauli Road, HARYANA. 70 units were collected by AIIMS blood bank team. Ms. Leena was motivating factor. Col. Bhutani's kind co-operation was really appreciable and he has given us permission for holding more Blood donation camps at DT Centre.

5. National Thalassemia Welfare Society organised a Blood Donation Camp in association with M/s. Craze, Enkay Towers/Centre, Banijya Nikunj, Phase-V, Udyog Vihar, Gurgaon, Haryana, on Tuesday, 19th August 2003. 41 units of blood were collected by Red Cross Blood Bank team. Mr. C.P. Lamba and Mr. Kumar helped us in successful organization of the camp. CRAZE sponsored refreshments to the Donors and lunch to the Medical team.

6. 21st August 2003 Blood Donation Camp at DLF Plaza Towers, DLF City Phase I, Gurgaon. 30 units were collected by AIIMS blood bank team. Mr. Om Prakash Munjal, Manager Maintenance took special interest.

7. National Thalassemia Welfare Society organised a Blood Donation Camp in association with Fluor Daniel, DLF Square, Gurgaon-122002 on Friday, 5th September 2003. 76 units of blood were collected by AIIMS blood bank team. Dir. (HR) Mr. Ashok Purohit, Ms. Bhavna, Ms. Shree, Mr. Shree Valsan, Ms Angmo helped us in organization of this camp. Mr. Tony Kretzehmar who has donated for the 46th times was also our estemed donor. The arrangement of the camp was highly appreciable. Dr J.S. Arora General Secretary National Thalassemia Welfare Society gave a highly motivational talk on Thalassemia & Blood Donation on 3rd September 2003 prior to the camp. The interaction of the audience was highly appreciable 19 persons also volunteered for the Thalassemia carrier diagnosis.

8. National Thalassemia Welfare Society organised a Blood Donation Camp in association with Shree S.S. Jain Shabha Nangal Raya, 1391/27-A New Delhi-110046, on Sunday the 21st September 2003. Parents of Thalassemic Child Mst. Abhishek Jain took special interest in organizing this camp. 40 units of blood were collected by DDU Hospital blood bank team.

9. **24 घंटे रक्त प्रवाह – Not for Drain but for Blood bank, THANKS to Mr. & Mrs. Rudra.**

   Daksh e.Services helped National Thalassemia Welfare Society in creating a history by organizing a Blood Donation Camp at its premises 186, Udyog Vihar, Phase1, Gurgaon-122016 on Thursday, 25th September 2003. The camp started at 9.00 a.m. on 25th and ended next day at 9.00 a.m. For the first time Society has organized a 24hrs day night blood

donation camp. 191 units of blood were collected by AIIMS and LNJP Blood bank teams.

Daksh has promised us another similar camp in near future.

Mrs. Vandana Arora & Mrs. Monisha deserve special appreciation for being force behind the organizations of all the blood donation camps at Gurgaon and that of M/s. Orion Dialog Pvt. Ltd., East of Kailash

Some motivated final year medical students of University College of Medical Sciences and associated Guru Teg Bahadur Hospital formed a group under the name and banner of **"Thalmed a.i."** to adopt Thalassemic children for providing blood. They organized first Blood Donation Camp in this regard on 25th August 2003 at GTB Hospital. They will be working in association with National Thalassemia Welfare Society and pledged to involve students from other professional and non-professional colleges to enlarge their group to adopt maximum number of Thalassemics.

NTWS organised **FREE** Hepatitis B & C screening Camp on 8th June, 13th July & 10th August 2003. Over 300 Thalassemics benefited from this. Positives were tested to the last leg of investigation, **which cost over Rs. 10,000 per child** in the market. Dr S.K. Sarin Director, Professor & Head GB Pant Hospital and his team helped us in organization of these camps.

Dr. Mamta Sharma HoD, Paediatrics DDU Hospital organized a seminar on Thalassemia on 26th July, 2003. It was inaugurated by Dr. K.N. Srivastva Medical Superintendent of the Hospital. Eminent speakers like Dr V.P. Choudhry, Col. Veelu Nair, Dr A.P. Dubey, Dr Suneel Gomber, Dr Madhulika Kabra enlightened the participants.

Dr Tripti Pancy Senior Consultant RML Hospital organized CME on Thalassemia Management – Recent Trends on 28th August 2003 at Hospital premises. It was inaugurated by Dr Salhan Medical Superintendent of the Hospital. Eminent speakers like Dr V.P. Choudhry, Dr Veena Doda, Dr Madhulika Kabra enlightened the participants

Dr J.S. Arora spoke on Prevention & Control of Thalassemia on both the occasions.

National Thalassemia Welfare Society organized FREE Bone Checkup Camp (Bone Densitometry) on 14th September 2003 at NTWS run Thalassemia Centr Tilak Nagar. 192 patients were benefited. It costs ov Rs. 1,000 in the market

National Thalassemia Welfare Society submitt following Memorandum to Mrs. Sushma Swaraj Hon'b Minister of Health, Govt. of India on 1st September 20

Request to grant "Disability status" Thalassemics for the purpose of PWD Act, 199

Request to take steps to create awareness throu Mass Media.

To provide Chelating agents to Thalassem Patients.

Thalassemia Screening & Control Programme Central Government Hospitals.

FREE Blood/Blood components to Thalassemi

Request for establishing National Haematologic Centre.

Request for exemption on custom duties equipments used in the treatment of Thalassemi

A Memorandum was submitted to Mr. Mahinder Sin Saathi, Hon'ble Finance Minister, Govt. of Delhi on September 2003 to abolish the Sales Tax on oral i chelating agent Deferiprone (Kelfer). He has assu to provide this benefit to Thalassemics.

नेश्नल थैलासीमिया वैलफेयर सोसाइटी की ओर से जनसाधारण में थैलासीमिया के बारे में बिल्कुल सरल आसान और आम भाषा में एक चित्रपट (docudrama का निर्माण दिल्ली सरकार के सहयोग से किया गया इस "चेतना" नामक docudrama को 27 मिनट की एक CD के रूप में प्रस्तुत किया गया है। इसका उद्घाट दिल्ली के स्वास्थ्य मंत्री माननीय डा॰ अशोक कुमा वालिया के कर कमलों द्वारा चतुर्थ नेश्नल थैलासीमिय कान्फ्रेंस के उद्घाटन समारोह में किया गया। इस CI की प्रतियां सभी उपस्थित participants को और प्रत्येक सोसाइटी को वितरित की गई। इसको विभिन्न राज्यों Cable T.V. के द्वारा दिखाया जा रहा है। यदि को संस्था अथवा व्यक्ति विशेष इस CD की प्रतिलिपि मंगवान चाहे तो संस्था से संपर्क करें। दूरभाष: 25507483

Readers Column

Q.1. Thalassemia patient should marry to Thalassemia patient or to a normal person?

Ans. A Thalassemia patient should not marry a Thalassemia patient. He or she may marry to a Thalassemia trait but the best option is to marry normal (not even trait) person.

Q.2. Can two adult Thalassemia patient's who take regularly blood & chelation therapy can marry?

Ans. Can, but should not.

Q.3. If two adult Thalassemia patient's who have married and have a child; will their child will be Thalassemia trait or Thalassemia major. Should they must not have a child and without child they both can have a normal life by adopting the child?

Ans. If two Thalassemia patients marry, their all children will be Thalassemia major. However if they still want to marry they can adopt a normal child.

Q.4. Should Inj. Lasix must be given Pre B.T. or Post B.T.? As I have noticed that some doctors and some hospitals do not use the Inj.?

Ans. Lasix help in reducing the blood volume caused by blood transfusion. It must be used when whole blood is transfused or when large volumes are transfused.

Q.5. During B.T. and after B.T. some patients have foot and stomach cramps? What should be done?

Ans. Cramps after blood transfusion may be due to calcium deficiency. Extra calcium may be given for few days or after checking the calcium status.

It is your column. Share your views & experiences and clarify your querries from the experts. You can sent any thing you like, Medical, Non-medical, Jokes, Poems whatever you like.

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

नहीं आसां डगर हस्पताल की
रहती है शंका मन में और सुईयों का डर
लगता है जब रक्त धमनियों में
भुजाओं में लग जाता है जर।

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

देखती हूँ जब मैं बच्चों को पंखों के संग
बंधा पाती हूँ अपने आपको भाग्य रेखाओं के संग
शिक्षा के आकाश में लोग उड़ते हैं उन्मंद होकर
रूक जाती हूँ राह में मैं मजबूर होकर।

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

दिया है जिसने हमें यह जीवन
दिया है सार्म्थय और ये दृढ़ मन
उसी का परिणाम है ये हम जीते हैं खुशी से
हमारी ताकत भी तो है उसी से

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

दी है जिसने ये हमें मिटायेगा वही
अपने नजरे कर्म से
देना इतनी ताकत प्रभु काम आये किसी के
हमारी भी ये जीवन काम आये यहीं पे

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

Wheet Grass Therapy आने से
सुना है प्राकृति ने सुन ली हमारी
आप लोगों के सहयोग से दवा उतारी हमारी
दवा को दुआ से मिला दो तुम
खुशिओं को हमारी जिंदगी में उतारो तुम।

थैलासीमिया थैलासीमिया यह है एक भयानक रोग
हम हैं इसके रोगी, नहीं इसका कोई जोग।

नित्या गुप्ता 46, शिवम एन्कलेव, रोहतक

Thalmed a.i. & "towards dawn...."

What is Thalmed a.i.

Thalmed a.i. is a voluntary group of 8 medical students who felt that issues which ought to be dealt by the students community were not even being taken up. So we decided well start with something we had been passionately into, voluntary blood donation and along came the realization that our voluntarily donated blood should be given to patients who can't get it from anywhere else, so we chose Thalassemics whose survival is dependent on donors like us. Hence started our pioneer project "towards dawn....".

What is "towards dawn...."

We of course one still in our recent stages therefore our objective are simple & straightforward.

1. To increase awareness about Thalassemia patients so that people can understand their needs.
2. To increase awareness about the his & how silently it might be affecting you & me.
3. To try & arrange for voluntry Blood donation exclusively for Thalassemics by student volunteers.
4. To try & ensure transparency in transit of blood from donors to recipient Thalassemics.
5. To handle academic projects regarding the subject of Thalassemia.

The aforementioned objectives are going to be dealt by our pioneer project "towards dawn...."

How can you help us

Become a part of us. Join us in the organization of our ideas & objectives. Become regular donors or become someone who wants to spread awareness. Choose what you want to do with us & let us try to fulfill you desire to work for this cause.

Our most important advise

All of us know our Thalassemia status through our blood reports. We advice you to know yours. A minor form of this disease – Thalassemia minor/trait might be affecting 30% of us. These people are absolutely normal but this might affect the progeny's future.

We are:

Anand Sanjiv
9891403579

Jain Harshit
9810405105

Mehta Rohitash
9811561062

Mittal Manoj Kumar
9868073174

Ravi Kant
9811764947

Sharma Sandeep
56039943

Tiwari Ambooj
9868449142

Verma Nishant

Blood Bank Organisation
Shanti Chambers (Opp. Telephone Exchange), 11/6-B, Pusa Road, New Delhi 110 005
Phones: 25721870, 25711055

BBO/2003-04/46 Dated 17-10-2003

Dr. J.S. Arora
General Secretary
National Thalassemia Welfare Society

Dear Sir,

This is to inform you that we have sufficient units of Packed Cells/Whole Blood in our stock. So, we are in a position to issue the same to the patients suffering from Thalassemia on your recommendation without replacement donor.

Besides these, poor patients can also avail this facility from our organisation. This is for your information and necessary action.

Yours sincerely,
Divya Lal, *Director*

SUPERBLIND

Erik Weihmayer, a blind man conquered Mount Everest, 29,035 ft high, the tallest peak on earth on 25th May, 2001. Not only this he has also distinction of climbing highest peaks of all seven continents.

Born with a rare genetic disease of the retina "Retinoschisis" Weihenmayer grew up knowing that he would be blind by the age of 13. Even after that, he fought to have an active life, filled with wrestling champions.

He climbs with a team, but does his share of the mountaineering work — carrying loads, setting up tents, and building snow walls.

Fellow climbers attach bells to their gear to direct him, but Weihenmayer is mainly guided by his own touch, In 1997 halfway up Africa's Mount Kilimanjaro summit, he married his wife, fellow climber Ellen Reeve, in a mountaintop ceremony. They now have a 2-year-old daughter, Emma.

Over the past seven years, one by one, Weihenmayer has conquered the seven highest peaks in all the seven continents.

Editorial comment: We would like to feature super Thalassemics in this column. Thalassemic who have achieved excellence or reached a new height in any field, send us your detailed information with documents and photos.

National Thalassemia Welfare Society (Regd.)

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Published by: National Thalassemia Welfare Society (Regd.) on behalf of Federation of Indian Thalassemics.

MEMBERSHIP

Any person can become a member of the society.

Charges	Inland	Foreign
Patron:	Rs. 5,000	US $ 500
Life:	Rs. 500	US $ 50

READY AVAILABLE

	(Rs.)
Filter Single Unit	450/- each
Filter Double Unit	550/- each
Infusion Pump	12,000/- each
Scalp Vein Set 27G	18/- each

SPECIAL THALASSEMIA CLINIC

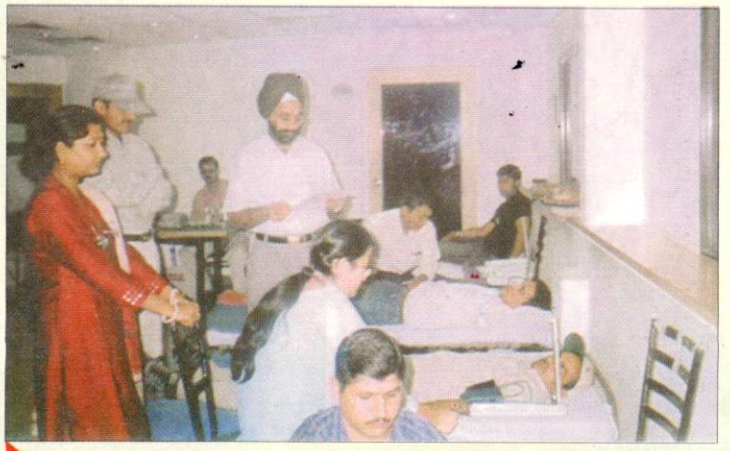
N.T.W.S. organises Thalassemia Check up Clinic ***on 2nd Sunday*** of every month at ***N.T.W.S. Thalassemia Centre,*** 2nd Floor, Community Centre, Slum & JJ Dept. of MCD, Block 12, Tilak Nagar, Near Gurudwara Singh Sabha, New Delhi–18. **For appointment contact:** Dr. J.S Arora, Tel: 011-25507483

Facilities:

- Growth Monitoring
- Chelation Therapy
- Serum Ferritin Assay for Rs. 150 only
- Hepatitis B vaccine: Rs. 50/- for Children below 10 years
  Rs. 100/- for Children above 10 years
- Thalassemia Screening/Diagnosis with HPLC Rs. 300/- only

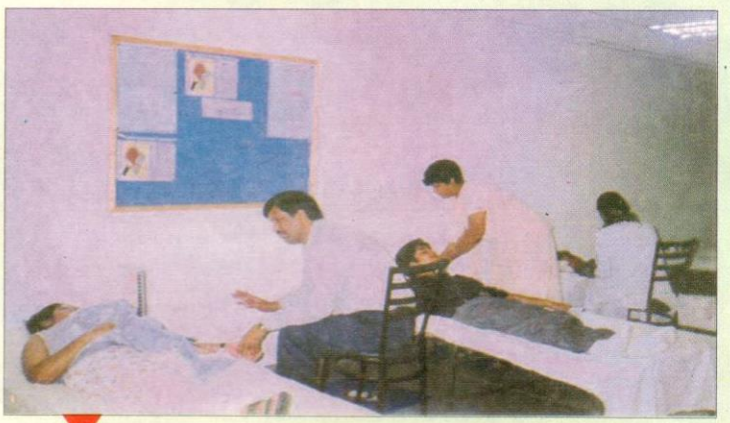
Blood Donation Camps Organised by National Thalassemia Welfare Society

24 hrs. Day & Night Blood Donation Camp Organised at Daksh, Gurgaon.



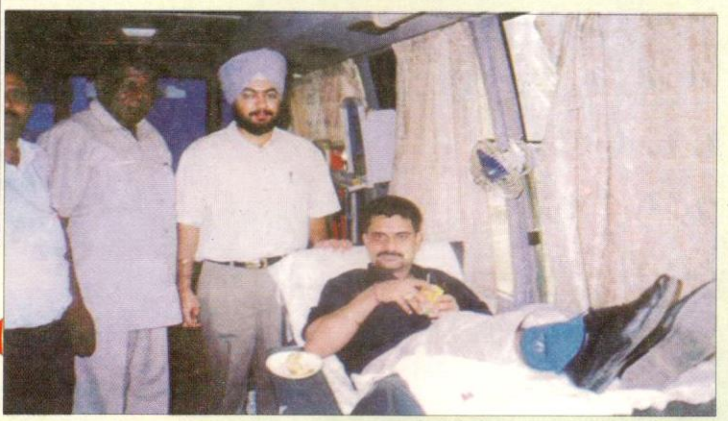
Dr. Swagata, Blood Bank Officer LNJP, & Dr. J.S. Arora seen at 24 hrs. Day & Night Blood Donation Camp, Daksh, Gurgaon.

24 Hrs. Blood Donation Camp.



Mrs. Rudra seen alongwith the AIIMS team 24th hrs. Blood Donation Camp Daksh Gurgaon on 25th Sept. 2003

Delphi Blood Donation Camp



A Thalassemic parent donating blood in Delphi Blod Donation camp.