

FEDERATION OF INDIAN THALASSEMICS
NATIONAL THALASSEMIA BULLETIN

EDITORIAL BOARD

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**A special and Heartiest Happy Birthday to
RACHIT ARORA (6th May)**

“हो भी क्यो न इस वर्ष” Rachit will be three years old on 6th May 2006 and he would celebrate his third birthday without any consternation of blood transfusions



5th National Thalassemia Conference on 11th & 12th Nov. 2006

at

Kalawati Saran Hospital

Organized by

National Thalassemia Welfare Society

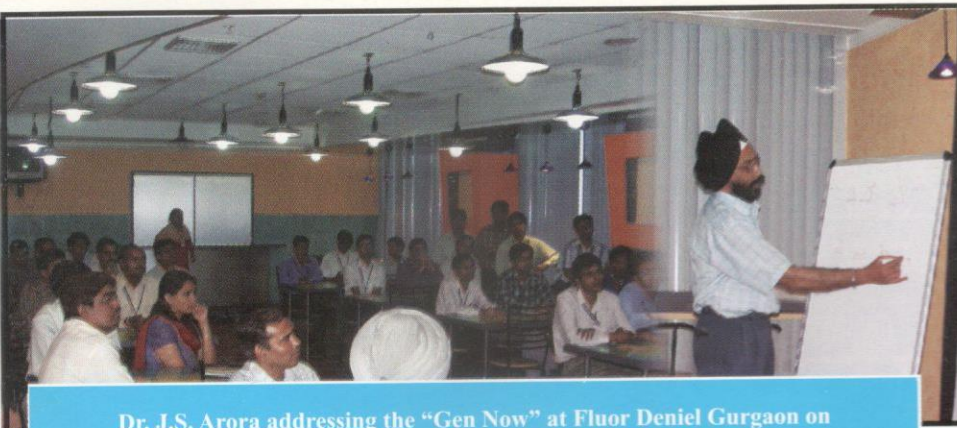
&

Department of Paediatrics Kalawati Saran Hospital

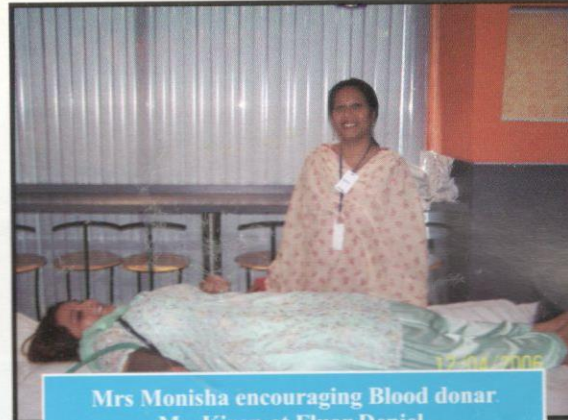
**Pre - marriage tests now a must in UAE
including thalassemia & sickle anaemia**

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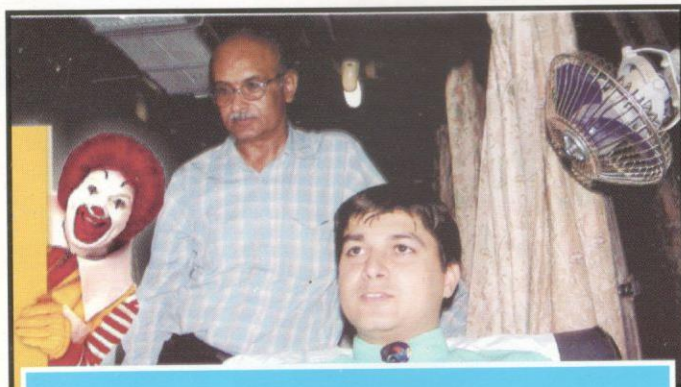
Dr. J.S. Arora, General Secretary, Federation of Indian Thalassemics,
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Dr. J.S. Arora addressing the "Gen Now" at Fluor Deniel Gurgaon on 11th April 2006 at Fluor Daniel, DLF Square, Gurgaon.



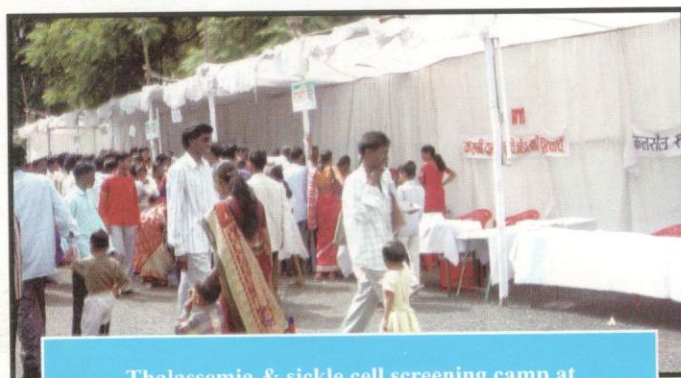
Mrs Monisha encouraging Blood donor Ms. Kiran at Fluor Deniel, 12th April 2006



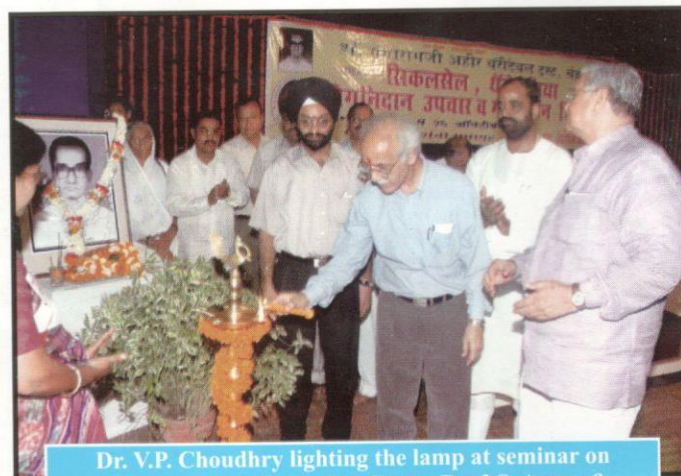
Mr. Ashok Sachdeva at Mc. Donalds, Rajouri Garden, Blood Donation Camp.



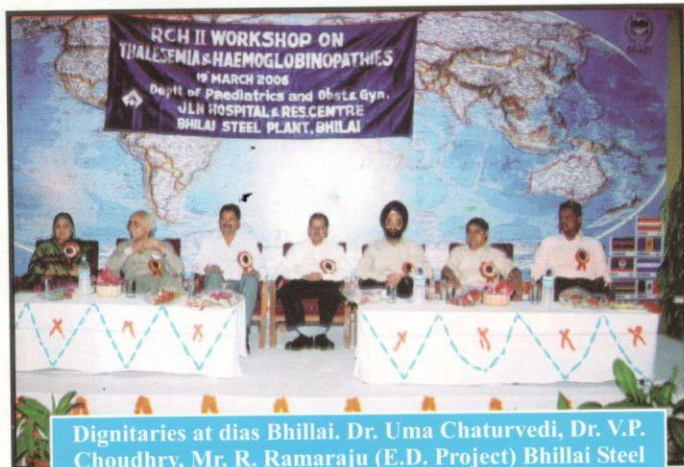
Inauguration of 3rd International Sickle Cell Disease Update - 2006, Nagpur.



Thalassemia & sickle cell screening camp at Chandrapur Maharashtra.



Dr. V.P. Choudhry lighting the lamp at seminar on Thalassemia & Screening Camp. Dr. J.S. Arora & Mr. Hans Raj Ahir M.P. Chandrapur (Maharashtra) Seen in picture.

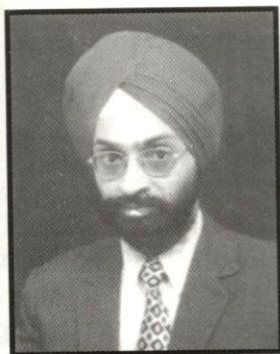


Dignitaries at dias Bhilai. Dr. Uma Chaturvedi, Dr. V.P. Choudhry, Mr. R. Ramaraju (E.D. Project) Bhilai Steel Plant, Dr. P.S.A Sharma, Dr. J.S. Arora, Dr. P. Panigrahi and Mr. Pramod Puri.



Mr. R. Ramaraju (E.D. Project) Bhilai Steel Plant, Bhilai among the audience.

EDITORIAL



The 10th biannual International Conference on Thalassemia and Haemoglobinopathies and parallel 12th International TIF Thalassemia Conference for Patients and Parents, held at

Dubai World Trade Centre in January 2006, were among the most successful ever. The two events are held simultaneously in order to facilitate the sharing of information between key stake holders in Thalassemia world-patients, parents, medical practitioners & scientists.

Almost 1000 patients and 700 health professionals, including representatives from WHO attended proceedings at Dubai. Delegates to the 2006 International Conference on Thalassemia and Haemoglobinopathies gained critical insight into major developments in the field, including endocrinology, liver disease, viral hepatitis, Thalassemia Intermedia, sickle cell disease and the epidemiology of Thalassemia, as well as prevention, psychology aspect of haemoglobinopathies, and patient survival and quality of life. There was also focus on therapeutic options in Thalassemia, particularly gene therapy. (source TIF Magazine)

It's not possible for most of us to go abroad and participate in International Conferences. National Thalassemia Welfare Society is organizing **5th National Thalassemia Conference on Saturday & Sunday the 11th & 12th Nov. 2006 at Kalawati Saran Hospital. Besides other developments introduction of new oral iron chelator EXJADE (Defrasirox ICL 670) would be star attraction.** EXJADE is once a day iron chelator which can be taken by mouth. It is likely to be introduced in India by the end of 2006. If you don't get brochure by the end of May 2006, please do not hesitate to ask from the undersigned.

Anjali's project on Thalassaemia has been selected in top 10 out of 10,000+ entries all over India. She has finals in Bangalore in the last week of April 2006, and if qualified in best three, she will get a chance to present it abroad in U.S. And it is being sponsored by "Microsoft".

Pre-marriage tests in UAE

Couples in the UAE will now be subjected to pre-marital tests for screening of different diseases a move by the Ministry of Health that aims at producing a healthy future generation.

Both UAE nationals and expats preparing to tie the knot in the UAE will now have to produce an 'all-clear' certificate before they can get their marriages registered, said the UAE Minister of Health, Humaid Mohammed Obaid Al Qutami yesterday after chairing the first meeting of the specially formed Higher Scientific Committee for Premarital Tests.

The minister said: "No couple will be stopped from getting married even if the results of the tests are positive."

"A standard health criteria committee will also provide technical advice to couples after evaluating them medically," he added.

Dr Amin Hussain Al Amiri, Director of Blood Transfusion and Research Services, who is also the Vice-President of the committee, said: "Eight major diseases will be monitored by the committee, and later a public awareness programme will also be held."

The diseases that couples will be screened for include thalassaemia, sickle cell anaemia, hereditary diseases, STDs/HIV, tuberculosis and other chest diseases as well as Hepatitis B and C.

He also clarified that in case the couple was found to be suffering from any of these diseases, the committee would provide them with counselling and also inform them about the treatment methods.

When UAE Govt. can opt for pre marital screening then why not Indian Govt.

Do not wait till Govt awakes, adopt it right now, after all it is in YOUR interest.

Dr. J.S. Arora

BMT at Dept of Haematology, AIIMS, New Delhi

RACHIT s/o Mr. & Mrs. Vinod Kumar Arora r/o village Pipalia sily jageer, Tehsil Bahedi, Dist. Breilly UP born on 6-05-2003 was diagnosed to have Thalassemia major at the age of 3 months and was put on regular Transfusion. He was found to be HLA identical with his sister, PRAJAKTA (Age 9 years) in November 2004. Rachit started iron chelation from January 2005.

At the age of 2 years & 6 months he was admitted for BMT at department of Haematology AIIMS under Pof. Dr. Rajat Kumar on 22.10.2005. He had total 28 Transfusions till 23/10/05. Liver biopsy reported marked increased iron in the liver, (Lucarelli stage III)

Hickman line was inserted on 27.10.05 under general anaesthesia. The preparative regimen consisted of Busulfan, Inj Cyclophosphamide and Inj Antithymocyte globulin. There were no complications.

Bone marrow was harvested from the donor under general anaesthesia on 17 Nov 2005. About 300 ml was harvested.

Engraftment was uneventful.

The Absolute neutrophil count of $> 500/\text{cu mm}$ ($1000/\text{cu.mm}$) was attained on Day + 15 (2.12.05) and unsupported platelet counts of $> 20,000/\text{cu mm}$ was achieved on day + 32 (19.12.05).

He was discharged on 28.12.05. At the time of discharge his Haemoglobin was 9.5gm/dl, TLC 5100/cu mm, DLC - Neutrophil- 42, Lymphocytes 46, Eosinophils 04, Monocytes 07, Basophils 01, Platelets 1.5-2 lacs/cu mm, Blood Sugar level, Liver Function and Kidney Function Tests were normal

At the time of discharge he was well, active, with good appetite and no infection or GVHD.

The child is now at home in Bareilly. There is full donor engraftment. After completion of 1 year, all medications will be stopped. He will be re-immunised. Till that time he needs to be protected from infections.

Financial assistance was given by the National Thalassemia Welfare Society and UP Government. Dr S.K. Sardana and Dr. Mrs I.J. Sardana of Breilly put special efforts in motivating the family and raising funds.

TIF Awards 2006

In the course of each bi-annual Thalassemia International Conference, it has become an institution to award two prizes to individuals with outstanding contribution to Thalassemia Worldwide. The first is the 'Panos Engelos' prize which is awarded to a scientist for his/hers exceptional contribution in the field of Thalassemia research and the 'George Engelos' prize which is awarded to a person-non-scientist, for his/hers outstanding contribution in the promotion and control of Thalassemia around the world.

The International Conference in Dubai this year was no exception in the course of this Conference two outstanding personalities were awarded the above-stated prizes, The late Dr. Panos Ioannou was awarded with the 'Panos Engelos' prize for his invaluable contribution in the fight to finding a cure for Thalassemia, while Mr. Mahesh, from Malawi Africa, was awarded the 'George Engelos' prize for his multifaceted social contribution in the promotion of Thalassemia.

'Dr. Panos Ioannou, a prominent scientist was very influential to many and dedicated his working career to help patients suffering from many genetically inherited diseases, especially Thalassemia. One of his very first activities was the setting up the prenatal diagnosis programme for Thalassemia in Cyprus, which has resulted in a dramatic reduction in the number of patients born with this severe disease and additionally worked to provide a better quality of life for those already affected.'

Dr. Michael Orford

3rd International Sickle Cell Disease Uptade-2006

13th - 15th January 2006, Nagpur.

As a part of continuing Medical Education Programme of R.H.D.M.C. I.G.G.M.C. Nagpur, IIIrd International Sickle Cell Disease Update-2006 was organized from 13th to 15th January 2006. This was a joint venture of R.H.D.M.C. I.G.G.M.C., Nagpur (functioning since last 5 years) & Sickle Cell Association Nagpur (NGO functioning since last 1 year) Departments of Paediatrics, Gynaecology, Radiology, Medicine were Co- hosts for this conference. Dhruv pathology Lab. Nagpur collaborated with R.H.D.M.C. in arranging workshop on 13th January 2006.

Aim of this activity was to bring together researchers & clinicians across the country-

1. To discuss various aspects of SICKLE CELL DISEASE related to epidemiology, newer trends in diagnosis and management.
2. To prevent mortality and morbidity in Sickle Cell Disease.
3. To explore possibilities to work together at Government/Non-Govt level.

This activity was partly funded by MCI, M.U.H.S. Nashik, Biorad Mumbai & SCAN., International & National experts along with delegates from other state and from the state of Maharashtra attended the conference. Delegates belonging to medical, para medical, technical & social workers have participated accordingly.

In this three day activity, on 1st day (13th Jan. 2006) workshop on prenatal diagnosis was held, while 2nd & 3rd days (14th & 15th Jan. 06) were devoted to CME. On 13th workshop on Prenatal Diagnosis was inaugurated by Dr. Graham Serjeant from Jamaica. He congratulated the organizers for creation of additional facility of chorionic villous sampling at the Deptt. of Radiology & PCR at Dhruv Pathology Laboratory, Nagpur. Dr. Purnima Satoskar congratulated the team for taking lead & making this facility available for the first time in central India. Dr. A.V.Shrikhande highlighted the importance of Prenatal Diagnosis as an option available to carrier couple for preventing the birth of Sickle Cell Disease baby. Following inauguration, lectures were delivered by the guest speakers on Genetics & Epidemiology, Pregnancy & SCD, counselling, lab & its application for prenatal & chorion villous sampling and PCR. In the

afternoon inauguration of PCR facilities for Sickle Cell Disease at Dhruv pathology lab was done by Mrs Berryl Serjeant. Hands on training about PCR was given to participants by Dr. Bankar & Dr. Shailendra Mundada to delegates having lab interests. At the same time Dr. Purnima Satoskar gave demonstration of chorion villous sampling at Deptt. of Radiology I.G.G.M.C. Nagpur to delegates with clinical Interest. Total number of delegates who attended the workshop was 86, out of which 58 from Nagpur & 28 were outside Nagpur, of these 13 were Gynaecologists, 8 Paediatricians, 14 Physicians, 8 technicians and 43 Pathologists.

On 14th morning CME programme was inaugurated by Dr. Graham Serjeant. He in his key note address appreciated the hard work of Indian doctors in making efforts for bringing down the prevalence of Sickle Cell Disease. He stressed the need for studying natural history of the Indian Sickle Cell Disease and to find out its solutions. He stressed the need for National Health policy for SCD and its inclusion as priority in the future plans. He hoped that Indian Govt. at Central and or State level would become active partner and lead this fight against SCD from the front. Dr. Ved Prakash Mishra as guest of honour in his speech picked up the idea and suggested that a white paper on sickle cell disease situation in india-problems & solutions be brought about and submitted to policy makers at various levels. He promised to help in just cause as member of Planning Commission & MCI. Dr.Mrs. A.V.Shrikhande in her speech appealed to all to think on these issues and came out with suggestions and promised that she will coordinate the efforts and RHDMC, IGGMC Nagpur along with SCAN, Nagpur will take the initiative to move forward in this direction.

In the scientific programme eight lectures on various aspects of Sickle Cell Disease were held following which interesting HPLC cases were discussed.

On 15th January morning eight lectures on various aspects of SCD were held followed by panel discussion on SCD and new born and SCD prophylactic vaccinations. In the afternoon session six lectures were held following which public forum for patients, parents, families and social worker was held. It was attended by about 100 Patients and Parents. Experts in various fields of medicine answered queries from patients/parents. Reassurance

was given to patients/parents that patients and doctors will work together to get each affected family its dues in terms of medical, social help.

A meeting of subject experts was held on 15th in presence of Mr. C.L.Thool Commissioner Human Rights, Mumbai to discuss matters relating to preparation of white paper. It was unanimously resolved that all possible efforts will be made to make policy makers aware of the problem and appeal to them to include SCD as priority Health problem. It was decided that a Brief Draft Proposal will be brought out and be sent to Hon'ble Secretary Medical Education & Drugs Deptt., Mumbai, D.M.E.R. Mumbai. Dr. Desai, Additional Director, R.C.H. programme, Gujarat, Dr. Ved Prakash Mishra, Vice Chancellor, Deemed University, Datta Meghe & M.C.I. Member, Nagpur.

Dr. V.P.Choudhary, Prof. & Head, Deptt. Of Haematology, A.I.I.M.S., New Delhi. Dr. A.R.Dalla, Vice Chairman & President Sick cell union of Cross Society, Raipur (Chattisgarh). Dr. S.L.Kate, Ex. Professor of Biochemistry & Chairman, Maharashtra

Aarogya Mandal, Hadapsar, Pune. Dr. B.C.Kar, Ex. Professor. Deptt.of Medicine, V.S.S.M.C., Burla, Orissa, SCAN Nagpur for inviting comments & suggestions.

During three day activity scientific paper in the form of posters were presented by various Institutions. Poster evaluation committee judged the papers for prizes. At the valedictory function children suffering from SCD felicitated the panellist and guest speakers. The organizers thanked Hon'ble, Secretary Medical Education & Drugs, Directorate Medical Education & Research, Directorate of Public Health, of Govt. of Maharashtra, Hon'ble Mr. C.L.Thool, Commissioner, Human Right, Mumbai, all International & National faculty & Chairmen of various Scientific Sessions & delegates for taking active participation in the conference.

CME was attended by 81 delegates, 60 from Nagpur, 21 from outside. Delegates belonged to various specialities Gynaecology-8, Paediatric-15, Medicine-15, Technicians-6 & pathologists-37. Dr V. P. Choudhry and Dr J.S. Arora were invited from Delhi as guest speakers

1st Workshop on Thalassemia & the Haemoglobinopathies at Bhilai.

A one day workshop on Thalassemia and other haemoglobinopathies was organised on 19th March 2006 at Bhilai Niwas, Bhilai with J.L.N Hospital and Research Centre, Bhilai. It was inaugurated by Mr. R. Ramaraju (E.D. project) Bhilai Steel Plant, Bhilai by lamp lighting.

Dr. Uma Chaturvedi (Joint Director, Medical and Health Services, J.L.N.H & R.C. Bhilai) welcomed the guests and the audience. Dr. V.P.Choudhry (Prof. & Head, Dept of Haematology, AllMS New Delhi) and Dr. J.S. Arora (General Secretary F.I.T. New Delhi) explained the purpose of their visit and stressed the need of improving facilities for Thalassemia & SCD patients and necessity for war footing efforts for the prevention of haemoglobinopathies. Dr. P.S.A Sharma (Director, J.L.N.H & R.C. Bhilai) addressed to the audience that he is in the process to provide the Leucocytes depleting filter to the patients. Dr. P Panigrahi (Joint Director and Head Dept of Obstetrics and Gynaecology, J.L.N.H & R.C. Bhilai said that he will do his best for Thalassemia screening.

Chief Guest, the executive director (project) of Bhilai Steel Plant Bhilai Mr. R. Ramaraju said that he will do

his best to start Thalassemia screening programme in this area. He also said that he will try to give more concessions to Thalassemia patients for blood transfusion who are not even employees of Bhilai Steel Plant.

A report on activity was presented by Mr. Pramod Puri (General Secretary, T.W.S, Bhilai)

Dr. V.P. Choudhry addressed about sickling its Cause, Care and Control. Thalassemia was extensively covered by Dr. J.S. Arora. He explained each and every aspect of its Care, Control, Iron Chelation and good management. They also examined the patients and advised to maintain Hb above 10 gm and to start chelation

Doctors of paediatrics and Obs & Gyno department of J.L.N.H & R.C, Bhilai Steel Plant, I.A.P. members, nurses, nursing students, teachers' nurses, patients, parents and general public were among the audience.

Above event was very well covered by press and electronic media. Mr. A.K. Choudhry, S.S. Sidar. & Mr. Suman worked hard for the success of the workshop.

National Thalassemia Welfare Society

MTNL Perfect Health Mela 2005

This year Perfect Health Mela was organised at Raja Garden Grounds opposite Shivaji College, New Delhi from 21st October to 30th October, 2005. We screened 400 volunteers by NESTROFT, 10% of them came out positive. They were advised Hb HPLC for confirmation. TV & VCD were installed and the film on awareness "Chetna" was shown the whole day. Exhibition Panels were displayed and brochures and posters were distributed amongst the visitors. Visitors included school children, college goers, medical staffs and nursing students. Most of the people were not aware of the Thalassemia disease and when they were explained and asked to do the screening test many of them denied saying they don't want to go for the test as they are OK. We had to put extra to convince them. The last day closing ceremony was supposed to be marked by the Chief Minister Sheila Dixit's visit. But due to the tragic incident of the serial Bomb Blasts in Delhi Chief Minister cancelled her visit and Industrial Minister facilitated the best participants National Thalassemia Welfare Society was honoured by certificate of appreciation.

Thalassemia Awareness & Screening Camps South Campus

A **Thalassemia awareness Seminar** was organised by the **Department of Statistics, Venkateshwara College, Dhaula Kuan, on 25th Nov'05**. The function was inaugurated by lighting lamp by the **Principal, Mr. Shankara Reddy, Dr. J.S. Arora & Mrs. Bansal**. The Seminar Hall was jam-packed with the students and Lecturers who gained lots of knowledge about the disease Thalassemia. **Dr. J.S Arora** delivered the talk through slide projection followed by viewing of the CD "Chetna". Interactive session generated so much enthusiasm that the Principal, Mr. Reddy promised us to held a Thalassemia Screening Camp as soon as possible along with a Blood Donation Camp. The students were very pleased to hear the Talk on Thalassemia and they promised to help the Thalassemic patients by donating blood and financially also. Mrs. Bansal, Prof. and Head of Statistics has planned this Seminar in her Department

and made exceptional effort to create awareness amongst the youngsters of Venky.

Gurgaon

National Thalassemia Welfare Society organized a Thalassemia Screening Camp on 15th September 2005 at **Inductis** an IT Company in **Vatika First India Place, Gurgaon**. Telefilm on Thalassemia awareness "Chetna" was viewed to all the employees followed by a talk by Dr J.S. Arora, 41 volunteers got themselves screened for Thalassemia and two came out to be a carrier after the confirmative test Hb HPLC.

Janak puri

National Thalassemia Welfare Society participated in **General Health Camp on 11th Dec 2005** at institutional area Janak puri organised by **BICODEP** an NGO Run by **Rotary Club Delhi Chanakya Puri**. Mrs. Seema Khurana Project Manager took special interest in creating the awareness.

Blood Donation Camps

1. A Blood donation Camp was organized at **Mc Donald's, 3 C's TDI Mall, Lajpat Nagar**, on 17th September 2005. Mc Donald's, Lajpat Nagar has given us the second blood donation camp in five months. The Mc D's Staff donated blood inspite of their tight duty schedules.
2. **Continuously for two days, Blood Donation camps were organized at Hero-ites, Gurgaon on 18th, October, 2005 & 19th October, 2005** from 9.00 PM to 3.30 AM. 99 units of blood were collected.
3. National Thalassemia Welfare Society regularly organizes **night Blood Donation Camps at MNCs** at Gurgaon. **Cybersys Infotech Ltd** organised a Talk on Thalassemia on **11th Nov'05 at 11.30 PM**. **Dr. J.S. Arora** was invited to deliver the Talk. The Seminar hall was jam packed with the audience. They were very thankful to come to know all about Thalassemia and Blood Donation. The next day **12th Nov'05** the **Cybersys Infotech Ltd, Gurgaon** organised a night Blood Donation Camp.

4. **Nishkam Sewak, Janata Market Jhandewala**, opp. Jhandewala Mandir organised a Blood Donation Camp for the first time in association with NTWS on **13th Dec'2005**. The S.H.O. Paharganj inaugurated the camp. It was covered on Astha TV Channel. Mrs. Monisha made appeal to the general public to come forward and help the Thalassemics by donating blood and financially. 57 units of blood were collected.

5. **Shah International School, Paschim Vihar** organised a Blood Donation Camp for the first time on **14th Jan 2006**. Ms. Neena Sharma principal of the school took special interest in organizing the camp.

6. **Nishkam Sewak, Janata Market Jhandewala**, organised another Blood Donation Camp on **17th Jan 2006**. 28 units of blood were collected Mr Vijay Khurana promised us a Blood Camp every month so that the Thalassemics get blood regularly. The Nishkam Sewak Sanstha has put up Hoardings on Thalassemia in the surrounding area of Jhandewala Mandir so that the devotees visiting the mandir can be made aware of the disease.

7. National Thalassemia Welfare Society organised a Blood Donation Camp in association with **Kamala Nehru Park Sudhar Samiti, Agrasen Marg, Gurgaon, Haryana on Sunday the 29th, January, 2006**. 28 units of blood was collected by the DDU hospital blood bank team. The blood donation camp was preceded by a talk by Dr J.S. Arora on Thalassemia awareness & blood donation motivation. The commendable feature of this meeting was that most of the MLAs & Councillors were present during the talk and they applauded the efforts of the society. Presence of politicians helps in success of any social project even if they don't involve actively.

8. Amrita Dhawan, Vice President, **Delhi University Students Union** helped us in organising a Blood Donation Camp in the North Campus on **14th February 2006**, the **Valentine's Day**. This Camp is being organized for the thfrd consecutive year on this day at the North Campus and the **Mc Donald's of Kamla Nagar** branch sponsors the refreshment of the Donors. 48 units of Blood were collected.

9. **The Mc Donald's Rajouri Garden** branch has organised a Blood Donation Camp for the first time. The Restaurant Manager Mr. Amit Arora's motivation helped

us to collect 45 units of blood within three hours time.

10. **The Nishkam Sewak Sanstha's** monthly Blood Donation Camp was organised on **28-02-06**. 38 units of blood were collected.

11. NTWS organised a Blood Donation Camp for the first time in **Institute of Law and Management Studies, Gurgaon**. A lecture was arranged to motivate the students and create awareness on Thalassemia. The students were also requested to get themselves tested for Thalassemia. 58 units of blood was collected on **20th March 2006** blood Donation camp and 18 volunteers got themselves screened for Thalassemia.

12. **Nishkam Sewak, Janata Market, Jhandewalla** in association with NTWS organized another Blood Donation Camp on **21st March 2006** & collected 26 units of blood.

13. NTWS organised a Blood Donation & Thalassemia Screening camp on **12th April 2006** for the first time in **Siri Fort Computer Technology and Management Institute, Rohini**. They invited Dr. J.S. Arora for a talk on Thalassemia on **11th April 2006**. DDU hospital Blood Bank team collected blood.

14. **Fluor Daniel** employees donated blood for the Thalassemics on **13th April 2006** for the third time. It was very successful camp where 125 units of blood were collected. 84 volunteers were screened for Thalassemia. AIIMS Blood bank team have collected blood.

World Disabled Day

National Thalassemia Welfare Society participated in the celebration of 'World Disable Day' **3rd December 2005** at the famous "Amar Jyoti" India Gate. The function was inaugurated by Chief Minister Mrs. Sheila Dixit. The Disabled children performed the variety cultural show and proved that how active they are and there is nothing impossible in this world.

NTWS also participated in the pre-rail budget "Dharna" organized by DRG, NCPEDP & other disabled organizations out side the residence of Rail Minister Mr Lalu Prasad Yadav in support their demand to provide better facilities for disabled people.

PICNIC

Thalassemia Picnic was organised with great joy and fun on 25 Dec. 2005. There was a huge gathering of Thalassemia families and invited guests. Children enjoyed very much at the lawns of India Gate. The day started with variety cultural performances of the Thalassemia children, and then followed by races and sports. There was a drawing competition where all the children participated. The children won prizes and enjoyed the whole day. Tambola was favourite game both among children and adults. Dr. J.S. Arora read the annual report of the activities done by the Society during the preceding year. President Km. Surrender Saini presented the prizes won by the children and honoured our sponsors with mementos. Delicious lunch was enjoyed by all the families sitting together. The Picnic ended by giving return gifts to all the Thalassemic children.

Fluor Daniel has been supporting us for last three years financially and voluntarily donating blood. They have

sponsored the Thalassemia Picnic which was organised on 25th Dec'2005. They have donated two Infusion Pumps for Desferal Therapy to our Society. NTWS is grateful to the Director, and the Staff of Fluor Daniel.

DESPAT (Delhi Society for Prenatal diagnosis And Therapy) organised cultural evening to create awareness on about genetic disorders on the final day of their conference. The children of **National Thalassemia Welfare Society** participated in the event. The Thalassemic children Somya Tripathi, Tanu Verma, Vandana Palta, Jyoti Gauri, Diksha Kohli & Wazeer Singh performed poem, song, dance & "tappe" respectively. Mrs. **Juhi Chawla**, the chief guest of the function was very happy to be invited in this conference and she shared some personal experiences with the doctors and the audiences and promised her support in prevention of genetic disorders in our society.

Chandrapur Conference

Mr Hans Raj Ahir Member of Parliament from Maharashtra organized an awareness and screening camp on Thalassemia and Sickle Cell Anaemia at his Chandrapur constituency on 15th and 16th October 2005. About 3000 persons were screened for these two haemoglobin disorders. Prevalence of Sickle Cell is very high among tribal population of Madhya Pradesh, Maharashtra, Gujarat, Andhra Pradesh, Kanataka & Orissa. Double heterozygote of Sickle and Thalassemia are also very common in these areas. On Sunday the 16th oct 2005, a seminar on Thalassemia and Sickle Cell Disease was organized. Besides general public, it was well attended by complete political brass and medical fraternity of Chandrapur and adjoining districts.

Dr J. S. Arora made elaborate presentations on 1) Prevalence & Diagnosis of Thalassemia & Sickle Cell Anaemia, 2) Prevention & Control of Thalassemia & Sickle Cell Anaemia and Dr V.P. Choudhry updated them on Management of Thalassemia & Sickle Cell disease.

Mr Hans Raj Ahir assured that The "Dr Ganga Ram Ji Ahir Charitable Trust" would provide all possible help to Thalassemics & SCD patients

Report from Bhilai

THALASSAEMIA Welfare Society. Bhilai. organised a lecture series as part of its thalassaemia awareness campaign at Bhartiya College of Agriculture and Agriculture Engineering at Pulgaon Naka, Durg. Eminent social activist Ratna Naramdev was the chief guest.

Mr. Pramod Puri, General Secretary of Thalassemia Welfare Society elaborated on the reasons and precautionary measures concerning the disease and exhorted them to initiate medical check up for both the bride and bridegroom to avoid the ailment in future generation. He also clarified several misconceptions concerning blood donation. Chief guest Ratna Naramdev exhorted the students to undergo Thalassemia screening test voluntarily and specifically appealed to them to donate blood for the needy patients. She also stressed that even the donation of one units of blood once in a year by a student can extend the life of a child suffering from thalassaemia by three to four weeks.

A K Choudhari, Father of a three and a half year old child Vishal suffering from Thalassemia, effectively apprised the students about his plight along with that of his other family members due to anxiety concerning the ailment. NSS Officer D K Tiwari also addressed the students and insisted them to undergo necessary blood tests before getting married.

Dec 26th 2005

Dear Dr. J.S. Arora

Namaskaar

Just received The Thalassemia Bulletin of You '05. I am Submitting my experience with wheat grass juice Therapy:-

My daughter Nandini is 19 Years old and receiving regular blood transfusion since the age of nine months i.e. Aug 1987. In June 2004, we went to Baba Ramdev ji's Camp at Haridwar who prescribed wheat grass juice with "Neem-Giloy". From 20th June 2004 we started the juice therapy fortunately "Neem-Giloy" is available in our town.

It has been 18 months since we started and we are feeling positive results for last six months. Nandini is now feeling comfortable, earlier she used to become anemic in 10 days of the BT now the period has entered upto 15 days and even than she feels comfortable except during menstrual period. The periods are quiet normal and regular.

He added on telephone that Nandini is maintaining pre-transfusion Hb over 9gm/dl on both the regimens i.e. earlier on 10 days interval and now alongwith wheat grass therapy 15 days interval.

For Iron chelation she takes Kelfar 500mg 6 caps daily. **Now her serum Ferittin is below 1000** but she is taking Kelfar regularly, colour of urine is also normal instead of reddish due to Kelfar. **Her liver & spleen has regressed now.**

As Nandini is 19 years old she understands her disease and other abnormalities and changes in the body, she is satisfied with the therapy.

We strongly recommend and appeal to parents to start the Therapy immediately which is the only way to keep your child near normal, side by side Iron chelation & regular blood transfusion.

Thanking you for the work being done on Thalassemia.

Truly yours

Ashok Vijay

c/o Swastik Sales, Khoja Gate Road, Boondi Rajasthan 323001

Tele-(0747) 2443493, 2442900, (m) 09414175759

Marriage & Thalassemia

When a patient becomes adult he/she has his/her own problems, these problems are different from those of younger patient's problems. The patient when reaches adulthood age, he/she thinks of a marriage because in our country when we say you are a normal being you should be married, if you are not married you are not normal.

So, adult Thalassemics when they think of their marriage their parent's start looking for proposals for their son or daughter. They take some efforts but they don't succeed in their effort's. Parents in their mind always have a negative approach for marriage of their Thalassemic child they think who will marry such a person who has to go for a Blood transfusion every 15 days for whole of life. In this way parents make their own child to go into depression. In my opinion if parents make 100% effort to get their child married they can easily do it. Parents should think if they had a child who is not a Thalassemic but had a different problem such as polio affected, blind or a physically handicapped they would have taken more efforts to get him/her married. I have seen a an adult person who did not have both the leg's got married to a normal girl, now they have a normal child this was because of their parents efforts. I have also seen many Thalassemic patients have got married.

Now I would like to tell patient's marriage is not everything in life but it is a part of life. If you get married I would be the happiest person on this earth keep trying one day you will get success. Till then don't get depressed by thinking of marriage you can do lot's of more things. The best way I think you should work for Thalassemia society. If you are doing a Job or business

or any other activity you should always have a goal in life. The ultimate goal in your life should be to help a Thalassemic patient in whatever manner it is possible by you. This will boost up your confidence as will as other patient's confidence; they will make you an ideal person.

The ideal patients in my life whom I have met till now are Gaurav Bose, Pranav Dhingra, Surbhi Sethi from Delhi, Sangeeta Wadhwa, Anil Vazarni from Bombay, Shilpa Arora, Simran Tejwani from Pune and many others whom I don't remember now.

Another matter that comes to my mind every time is why Indian medical community & parents are always against the marriage of a Thalassemic patient with another patient. I think this is the best concept in the world if two adult Thalassemics get married they will accept each other's necessity, as they have same problem they can fight that together.

As Thalassemia patient's who have got married to another Thalassemia patient will know that if they have a child it will be a major Thalassemia child. So they will not have child, they may go for adoption or for a test tube baby. If they don't want a child they can happily live together as they can go to transfusion and many other places together, if they were not Thalassemic couple they would not enjoy a transfusion together. When two normal persons get married their families support them then why not two families of Thalassemic patients support each other by getting two Thalassemic children married together, this way they can have a bigger support.

Jatin N. Sejpal

622, Rasta Peth Azad Chowk, Pune 411011

अधंकारमय मासूम जिन्दगी

आज के युग की भागदौड़ जिन्दगी इतनी तेज हो गई कि इन्सान को इन्सान की ही सुध नहीं है। ये भी उसे मालूम नहीं कि आज इस युग में क्या हो रहा है ? कौन जी रहा है कौन मर रहा है ? उसे तो खुद से ही इतनी फुरसत नहीं कि इतनी भागदौड़ जिन्दगी से दो क्षण का समय निकालकर इन मासूम बच्चों की तरफ थोड़ा ध्यान आकर्षित करूं मैं तो सिर्फ शारांष की भांति रख रहा हूँ। शायद हो सकता है आप मैं थोड़ी सी ललक उठे। आप द्वारा लिया गया निर्णय इन मासूम बच्चों के लिए आपकी प्रेरणा ही हो।

ये वो बच्चे हैं जो सिर्फ रक्त के सहारे ही अपना जीवन व्यतीत कर रहे हैं जिनको महीने में एक से तीन बार रक्त चढवाने की आवश्यकता पड़ती है सही मायने में तो ये बच्चे सिर्फ रक्त के सहारे ही अपना जीवन व्यतीत कर रहे हैं जिसे कि हम (थैलासीमिया) नामक रोग से जानते हैं

हालात अनुमान से कहीं गंभीर है। इनका भविष्य ही नहीं वर्तमान भी अधंकार से घिरा है। इसे दैवीये आपदा के रूप में दुर्भाग्य ने इन बच्चों को आपदा के लिए दस्तक दे दी है। हम इसे निराशा ही कहें या आशा का दीपक भी जलाये आशा और निराशा की इस घड़ी में इन बच्चों को जरूरत है हमारी और आपकी मदद की।

मदद के लिए भी अनेक प्रकार के रूप होते हैं, जैसे तन मन धन से

तन तन से आप इन बच्चों के लिए सबसे बड़ा दान जो है रक्तदान।

मन मन से आप इन बच्चों के लिए परमात्मा से प्रार्थना।

धन धन से आप यथासंभव आर्थिक सहायता।

इन बातों को हम छोटी कहे या बड़ी मदद को इनके लिए सहारा बन चुकी है। इन थैलासीमिया बच्चों के लिए मदद करना हम सब का राष्ट्रीय दायित्व ही नहीं नैतिक कर्तव्य भी है आप इस दायित्व का निर्वहन कर सकते हैं।

मेरा व मेरे साथ जुड़े सभी सोसायटियों का आपसे सिर्फ इतनी ही कि आप इस दायित्व को बेखुबी से निभाकर इन छोटे-छोटे मासूम बच्चों का पूर्ण सहयोग दे।

महेंदर कुमार

मजबूत हो इरादा तो ना रोक सके कोई बाधा

अजमेर, 20 नवंबर। मन में कुछ करने की इच्छा हो और सकल्य ढ हो तो कोई भी बाधा आपका रास्ता नहीं रोक सकती। थैलेसीमिया की जकड़ में बच्चों ने रविवार को आयोजित डांस व पेंटिंग प्रतियोगिता में अपनी प्रतिभा दिखा कर यही संदेश दिया।

अजमेर रीजन थैलेसीमिया सोसायटी की ओर से आयोजित डांस पेंटिंग प्रतियोगिता में थैलेसीमिया से

पीडित जिन्दगी और मौत के बीच का सफर तय कर रहे बच्चों ने दुःख तकलीफ को अपने आत्म विश्वास से दरकिनार कर अपनी कल्पनाओं में रंगभर कर उन्हें कार्डशीट पर उतारा तो लोगो ने दांतो तले अंगुली दबा ली। पेंटिंग प्रतियोगिता में किसी ने गणेश जी का चित्र बनाकर भक्तिभाव का परिचय दिया तो किसी ने नदी किनारे बसी बस्ती में अपने सपनों का घर बनाया। कुछ बच्चों ने मिक्की-माउस के कार्टून बनाकर अपने नटखट स्वभाव को प्रस्तुत किया।

अपनी बीमारी और उसके भयावह परिणामों से बेखबर बच्चों ने डांस प्रतियोगिता में भाग लिया

CONGRATULATIONS


Dr. Sumanlata Mendiratta

Senior Consultant, Department of Obstetric & Gynaecology, Hindu Rao Hospital New Delhi

The Federation of Obstetric & Gynaecological / Societies Of India awarded Dr. Sumanlata Mendiratta, **Dr. C.L. Jhaveri Prize 1st prize for the best Miscellaneous Paper Presentation, on "Cost Effective Screening for Thalassemia in Pregnancy"** during the 49th All India Obstetric & Gynaecological Congress held at cochin from 6th to 9th Jan 2006. Award also carries Rs. 500/- towards the prize amount.

Dr. Sumanlata Mendiratta has been actively supporting the cause of Thalassemia by promoting Thalassemia screening among pregnant women whenever they pay her first visit to antenatal clinic. Prevention of Thalassemia is in the hands of obstetricians. If every Obstetrician starts screening every pregnant woman on her first visit "to who din door nahi jab Cyprus, Sardinia, Italy, Greece ki tarah Bharat mein bhi Thalassemia ko niyantran mein kiya ja sakega". When every pregnant woman is screened for Hepatitis B & HIV (in most of the major cities and towns) the WHY NOT they can be screened for Thalassemia Carrier status when carrier rate of Thalassemia is MUCH-MUCH HIGHER than Hepatitis B & HIV i.e. 5.56% in Delhi (ICMR study).

NTWS congratulates Dr. Sumanlata Mendiratta for being awarded by the prestigious award and wishes her greater success in life



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Thalassemia patents in dire straits

KOZHIKODE, Problems related to blood transfusion are creating a near-crisis situation for the patients at the Medical College Hospital here. The reactions these patients undergo during the transfusion of blood include high temperature, vomiting, nausea, back pain, allergy and headache. Secretary of the Malabar Thalassemia Society, Kareem Karassery, pointed out that these reactions can be avoided only by providing the patients with 'leucocyte depleted packed red blood cell'.

Mr. Karassery said that though blood banks in the country had the facility to provide this category of patients with packed Red Cells, this is yet to be introduced at the MCH here. Memorandums in this regard had been given to K. Muraleedharan, MP, and the Union Health Minister. An appeal had also been made to the chief Minister.

"Despite a directive of the Union Health Ministry and the National Blood Transfusion Council not to levy service charge on Thalassemia patients, the State Health Department continues to impose it". Mr. Karassery said

OBITUARY

FIT and all the deepest grief and sorrow untimely sad demise of of Mr. Kareem Malabar Thalassemia Blood Patients Malabar zone, Phonix, last on 18-02-06 due to a problem. Ansif was a Science Student and he life working for the blood disorder patients in the Malabar area.



Thalassemics express on the sudden & Ansif 17 years old, son Karassery Secretary of Society & Convenor, Protection Council Salem. He breathed his severe cardiac Final year Board lead a very active social

May God bless the departed soul permanent peace and courage to the bereaved family to bear the irreparable loss & continue to serve for the noble cause

National Thalassemia Welfare Society (Regd.)

KG-1/97, Vikas Puri, New Delhi-110018 Tel : 55491151, 25511795

URL : thalassemiaindia.org E-mail : ntw@thalassemiaindia.org

MEMBERSHIP

Any person can become life membership of the society by filling a form & DD of Rs. 500/- in favour of : **National Thalassemia Welfare Society.**

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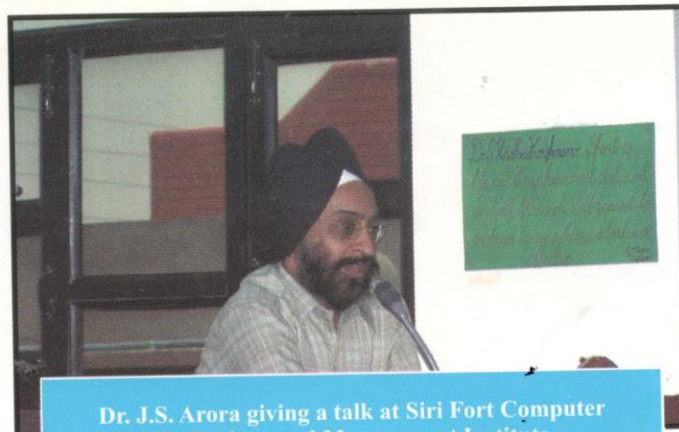
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Dr. J.S. Arora giving a talk on Thalassemia at Kamla Nehru Park, Gurgaon, 29th, Jan 2006. Local Political Leaders of Gurgaon sitting on the dais.



Dr. J.S. Arora giving a talk at Siri Fort Computer Technology and Management Institute New Delhi.



NTWS members enjoying picnic at India Gate on 25th December 2005.



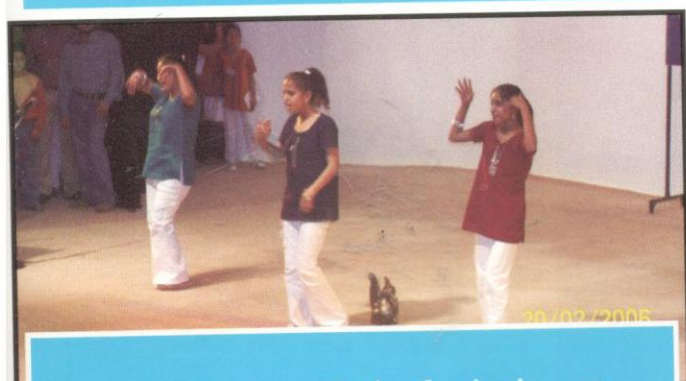
Mr. M.P. Gupta, Senior Manager, Syndicate Bank Nangloi, awarding the winners at Picnic Rudra inviting the Thalassemics who performed best in Sports & cultural activity.



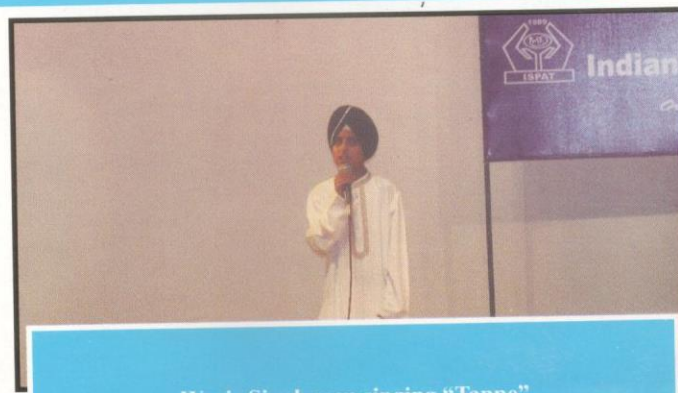
Somya Tripathi Rhyming a poem on Thalassemia.



Tanu Verma singing " ऐ मेरे वतन के लोगो.....
थेलासीमियां से जो पीडित जरा उनकी सुनो कहानी "



Diksha, Vandana and Jyoti performing dance on famous tune " जीने दो "



Wazir Singh seen singing "Tappe"



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