



FEDERATION OF INDIAN THALASSEMICS NATIONAL THALASSEMIA BULLETIN

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The 9th International Conference on Thalassemia & Haemoglobinopathies & The 11th International TIF Conference



**Mrs. Shobha Tuli, Dr. J.S. Arora & Ms. Madhuri Mehra among
the Indian delegates during the deliberations of the
9th International Conference on Thalassemia and
Haemoglobinopathies and the 11th International TIF
conference for parents and Thalassemics.
OCTOBER 15th - 19th, 2003 TERRASINI, PALERMO - ITALY**

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**NTWS Felicitate Dr. Ashok Walia on 31st Jan, 2004
for being elevated to the Hon'ble Minister of Finance, Govt. of NCT, Delhi.**



Dr. Ashok Walia, Hon'ble Minister of Finance assuring Dr. J.S. Arora, to waive off sales tax on Kelfer and full support from Delhi Govt.

Dr. J.S. Arora presenting a bouquet to Mr. S.P. Agarwal, IAS, Principal Secretary, Health.



Ms. Surrendar Saini presenting bouquet to Dr. K.N. Srivastava, Medical Superintendent, DDU Hospital.



Ms. Surrendar Saini presenting bouquet to Dr. Madhu Jain, M.S. Kasturba Hospital

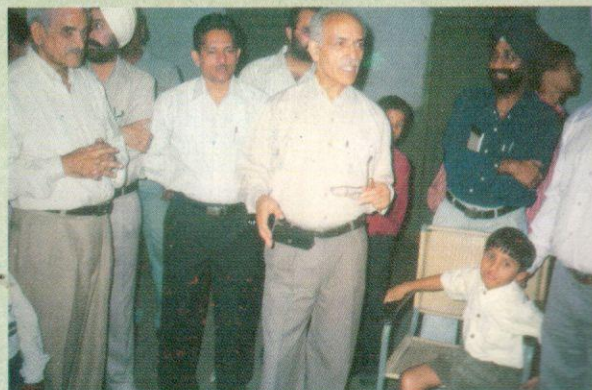


**Amritsar Thalassaemia welfare society organised
a seminar on 'Management and concepts of Thalassaemia on 1st & 2nd Nov., 2003**



From R to L

1. Dr. Geeta Sharma - Vice Principal
2. Dr. Mrs. Madhu Choudhry
3. Dr. P.S. Bedi - Principal Govt. Medical College, ASR
4. Dr. V.P. Choudhry - Prof & HOD Haematology, AIIMS
5. Dr. Mrs. Kahlon - Prof & HOD Haematology, ASR
6. Dr. Karnail Singh - HOD of Paediatrics, ASR



Dr. V.P. Choudhry addressing to parents of Thalassaemia

EDITORIAL



As life is an experience so has been TIF International Conferences for me.

The 9th International Conference on Thalassemia and The Hemoglobinopathies and The 11th Thalassemia Parent and Thalassemics International Federation Conference (TIF) was held at Palermo, Italy from 15th to 19th

October 2003. I have always wanted a big group of people from India to take part in such conferences. Apart from Ash conference no other conference have been imparting such levels of education, knowledge and experience as TIF conferences on Thalassemia. My wish seemed to fulfil to some extent when I heard that Dr. Sharmila Chandra and Dr. P. Choudhary (Kolkata), Dr. Rajiv Bansal (Jaipur), Dr. V.K. Khanna and Dr. J.S. Arora (Delhi), Dr. Praveen Sobti (Ludhiana) and a group of four Thalassemics and a parent (Delhi) will be travelling to Palermo. The day came when we all met each other at the lobby of the Hotel Citta Del Mare where the conference was held.

More than 1000 delegates took part in the conference from almost all parts of the World. The Scientific Committee had set up the programme in such a manner that there was a lot to hear on the newer therapies, and to learn more on the existing treatments. Psycho-social sessions were excellent from patients point of view. I was so pleased to see that Thalassemics are no more children and are growing to be the responsible adults and parents or would be parents.

The Conference also gave me the opportunity to meet old friends and make new friendships. As usual I was not interested to attend social dinners but preferred to spend time in small groups of patients and parents which gave us some personal experiences to share and to know each other better.

The News on ICL670 from Novartis is encouraging.

Talks on Gene Therapy give hope but I feel we still have to wait for some more time. BMT is the only curative therapy available to Thalassemics and it is best to be done in the early years of life (preferably before four/five years).

A lot of information being discussed at the conference is available with us at Delhi and also with other doctors who participated from Kolkata, Jaipur and Ludhiana. I feel parents should keep themselves in touch with their local doctors to be kept informed all the times.

We should be proud that our doctors are always ready to help us by giving us the right information and guidance.

In case you have any questions or you wish to seek further information, you are always welcomed to contact me at FIT or TIF and you will find me near you.

After I came back from the TIF conference I received a note from Ms. Anubha Taneja (a Thalassemic), which is the most precious note I have ever received. I wish to express my feelings in the same manner to all of you. We are all one for Thalassemia. As TIF has always said 'Unity is our strength' and FIT has been asking for more hands to join Federation of Indian Thalassemics, why wait? Perhaps today is the day when we can feel ourselves altogether and united.

With best and sincere wishes from all of us at FIT.

Shobha Tuli
President

**Heartiest Congratulations to
Mrs. Shobha Tuli
for being elected
President of TIF.**

Transdermal Estradiol Replacement Therapy in Hypogonadic Thalassemic Females: 14 Years Experience

A. Allegra, M. Capra, V. Mistretta, L. Cuccia, M.C. Traina

ANDROS Day Surgery – Reproductive Medicine Unit – Palermo, Italy (Source: TIF)

Introduction

Patients with β -Thalassemia require multiple blood transfusions leading to hemosiderosis.

These patients often have pubertal delay and gonadal function failure, the aetiology of which is probably related to the damage of pituitary gonadotrophs by iron deposits. The reason why the gonadotrophs seem particularly sensitive to iron overload is not clear.

In the past, children with homozygous β -Thalassemia rarely survived beyond adolescence. Today, with the improved medical treatments and iron chelation therapy, the survival is dramatically increased. Therefore, it is mandatory to guarantee to these girls a normal sexual development, regular menses and, at the same time, to avoid the side effects of estrogens deprivation. Furthermore, substitutive therapy is very important to prepare the genital tract of these patients for both sexual relationships and potential possible pregnancy.

The choice of estrogen replacement therapy must be done according to particular metabolic conditions of these patients.

Compared with classic oral estrogens therapy, recent transdermal route of administration has many advantages: lower dose, absence of hepatic first pass, better bio-availability and more physiological plasma levels. These features are more important in Thalassemic females that very often have hepatic damage and glucose intolerance.

Aim

The aim of our longitudinal study (14 years) was to evaluate the effects of estrogens transdermal replacement therapy associated with oral medroxyprogesterone acetate (MAP).

Materials and Methods

Since 1989 until May 2003, we followed 32 patients aged 13.4-24.2 with hypogonadotropic hypogonadism underwent replacement hormonal therapy. The substitution treatment was performed with estradiol using a transdermal therapeutic system (TTS) or with an association of TTS and oral MAP.

24 out of 32 girls were affected by primary amenorrhea and 8 out of 32 by secondary amenorrhea. We started the use of estrogens TTS in 1989 and the observed treatment period ranged from 2 to 14 years.

To induce pubertal maturation, the patients with Tanner stage \leq B2 PH2 were initially given a dose of 25mg twice weekly no stop for one year. Later, the following sequence was used: 50mg of estradiol TTS (twice weekly) for three weeks each month and 10mg of oral MAP daily was added after 10days from starting therapy for 10 days. The patients with a Tanner stage \geq B2 PH2 started with the combined therapy immediately.

During treatment, the dose was adjusted according to possible patient's side effects (i.e. breakthrough bleeding).

In the studied patients we analysed;

- a. Plasma level of estradiol during treatment
- b. The Tanner stage modifications
- c. Menses features
- d. Bone mineral density (BMD) of lumbar spine
- e. Drop out rate
- f. Patients lost to follow up
- g. Changes in therapeutic schemes
- h. Compliance
- i. Metabolic side effects and
- j. Sexual behaviour

Results

The plasma 17BE2 value observed during the second week of treatment was 74 ± 58 pg/ml, a value corresponding to normal early follicular phase range.

Tanner stage dramatically increased in all patients in the first 6 months of treatment and ultrasounds showed an increase of uterine size and uterine shape became of adult type.

In these patients we observed a particular shape of the breasts described as "tubular breasts".

Withdrawal bleeding occurred in all patients and in these cases we changed the therapeutic scheme (i.e. increasing the dose of MAP).

Spinal BMD was found lower than controls, but the bone loss was less marked than that found in reported untreated patients.

No patient abandoned treatment spontaneously. No patient was lost to follow up and only 3 abandoned the treatment for diabetic or hepatic complications.

6 patients stopped the treatment to become pregnant; those patients, who became pregnant, started therapy again after pregnancy and lactation. The Compliance was excellent in all patients. Neither systemic side effects nor adverse important metabolic side effects were observed.

Regarding sexual behaviour, we found that persons with β -Thalassemia were just as likely as their unaffected peers.

Conclusions

Our data show that estrogens transdermal substitutive therapy associated with oral medroxyprogesterone acetate determines a normal sexual development in β -Thalassemic adolescents.

Furthermore, according to Lasco et al, "long term" treatment improves bone density parameters and guarantees regular withdrawal bleedings to these women. Neither important systemic side effects nor adverse

metabolic effects were observed. Thus, we believe that substitutive sex steroid therapy must be administered "long term" to Thalassemic females with an irreversible impairment of pituitary gonadal function. Moreover, we think that is mandatory to prefer transdermal route for estrogens administration.

Report on 9th International Conference on Thalassemia and Haemoglobinopathies and the 11th International TIF Conference for Parents and Patients.

The 9th International Conference on Thalassemia and Haemoglobinopathies and the 11th International TIF Conference for Parents and Patients was held on 15-19 October 2003 in Sicily, Italy had the goal of reviewing the state of the art in the field of Thalassemia and discussing the most relevant concerns in the field with international experts.

For this reason each session was followed by a panel discussion in which experts in the field tried to give a conclusive answer to the most burning questions in the field of Thalassemia and other haemoglobinopathies.

Besides others, the following important topics were discussed:

1. Molecular genetic of globin genes, any clues to therapies
2. Current status of research on foetal haemoglobin inducers.
3. Gene Therapy for Thalassemia - Will it become a reality?
4. Long term follow-up after BMT
5. Genotype Phenotype correlation.
6. Hypercoagulable state in Thalassemia
7. Hormonal Replacement Therapy and Fertility in Thalassemia major
8. MRI to evaluate liver and heart iron in Thalassemia
9. New Oral Iron Chelator ICL 670C
10. Prevention & Treatment in developing countries and the role of WHO, ECC & UNICEF.
11. Planning of future across years and hopes

Some of the topics will be covered in the News Bulletins.

थैलासीमिक युवतियों पर अद्यः त्वकः हारमोन चिकित्सा पर एक अन्वेषण

थैलासीमिया रोगियों में बार-बार खून चढ़ाने से शरीर में लोहे की मात्रा बढ़ जाती है जिससे अन्य अंगों के अतिरिक्त पीयूष ग्रंथि (Pituitary gland) पर भी इसका दुष्प्रभाव होता है जिससे किशोरावस्था में होने वाले शारीरिक परिवर्तन देर से होते हैं।

पूर्व काल में अधिकतर थैलासीमिक रोगी बचपन अथवा किशोरावस्था में ही मृत्यु को प्राप्त हो जाते थे परन्तु आजकल उचित चिकित्सा और लोह निष्कासक दवाओं के प्रयोग से उनके जीवन काल में काफी वृद्धि देखी गई है। अतः यह आवश्यक हो जाता है कि किशोर-किशोरियों को उचित शारीरिक वृद्धि, सामान्य प्रजनन विकास एवम क्रिया उपलब्ध कराई जाये। इसी संदर्भ में 32 लड़कियों पर 14 वर्ष तक अद्यः त्वकः एवम मौखिक हारमोन चिकित्सा द्वारा एक अन्वेषण किया गया।

इसमें पाया गया कि 6 मास की चिकित्सा से जननांगों का समुचित पूर्ण विकास हो जाता है। अस्थियों में भी पहले से अधिक मजबूती पायी गई। 3 रोगियों में मधुमेह और ज़िगर रोग के कारण दवा बंद करनी पड़ी तथा 6 में अस्थि रूपांतरण से गर्भ धारण के कारण दवा बंद की गई जोकि स्तनपान के बाद पुनः शुरू की गई।

अन्वेषण के दौरान किसी भी परिवार के दुष्प्रभाव नहीं देखे गये अतः ऐसी थैलासीमिक लड़कियों को जिनकी पीयूष ग्रंथियां पुनः कार्यान्वित नहीं हो सकती उन्हें लम्बे समय तक अद्यः त्वकः इस्ट्रोजन दिया जाना चाहिए।

Dayanand Medical College & Hospital (DMCH), Ludhiana

A novel programme named **Student Aid Thalassemia (SAT)** has been launched by Punjab Thalassemia Welfare Society to help the patients suffering from Thalassemia. The launch function was inaugurated by Ludhiana Deputy Commissioner Mr. Anurag Verma. The project was initiated with the efforts of Dr. Praveen Sobti, Reader Deptt of Paediatric and In-charge, Thalassemia Unit, DMCH in collaboration with the District Education Department. Under the programme every student in the school would be persuaded to donate Rs.1/- per month (EACH ONE GIFT ONE) towards the fund for the treatment of the Thalassemia children who need regular blood transfusion and other costly treatment.

DMCH has started 11-bedded Thalassemia Day Care Unit where admission and investigations are free for the children. PTWS has organized 11 blood donation camps in 2003 and collected 738 units of blood.

Mr. Verma, while addressing the function organised by the PTWS to honour the blood donors and the organisers, said the administration would extend continuous financial help for treating such children.

The Deputy Commissioner exhorted all voluntary and social organisations working for the service of the

suffering humanity to come forward to extend financial assistance to Thalassemia-affected children.

He informed that the Ludhiana Branch of the Indian Red Cross Society had already released funds amounting to Rs.7.30 Lakhs to the PWTS. He announced a grant of Rs.51,000/- on behalf of the Sutlej Club Ludhiana for the PWTS. On the occasion, Mr. Sunil Jain, Secretary, Sutlej Club, and Bakshi Mohinder Singh, President, Guru Teg Bahadur Charitable Hospital, announced donations amounting to Rs.1000/- and Rs.2500/- respectively. The Deputy Commissioner also honoured around 25 blood donors and representatives of the organisations for their services in this regard.

Thalassemic patients Baljit, a nursing student of Guru Teg Bahadur Hospital and two other children, Gurkamal and Damanpreet Kaur were also given prizes for excellence in studies.

Tanvi Puri, a student of Sacred Heart Convent School, gave an impressive Bharatnatyam performance on the occasion. Later, Thalassemic children displayed their talent through various song and dance items and were given prizes by the Deputy Commissioner.

Training Program on Thalassemia Care
Kalawati Saran Children's Hospital, Bangla Sahib Marg, New Delhi.
Saturday 3rd April 2004.

Objectives:

1. To train the Paediatricians & Physicians to provide holistic care to Thalassemia patients.
2. To enable the trainees in establishing Special Care Facility for Thalassemia patients.

Registration:

The **Registration Fee** is Rs.250 payable by Cheque or DD in favour of "Thalassemia Workshop" payable at Delhi. Please, add Rs.50 for outstation cheques. Only first 60 participants will be registered on "**First come First serve**" basis. Please, send your short CV also. Last date for registration is 29th Feb 2004. No on the spot registration. For queries related to local accommodation and travel secretariat may be contacted. Brochure will be sent on request.

Secretariat:

Thalassemia Day Care Centre, Kalawati Saran Children's Hospital, Bangla Sahib Marg, New Delhi-110001.
 Telephone: 23344160 Extension: 402, 418, 411. Email: jagdish@pediaindia.net

Organised by:

Department of Paediatrics, Lady Harding Medical College, and Kalawati Saran Children's Hospital, New Delhi, Indian Academy of Paediatrics, Delhi State Branch, IAP PHO Chapter, and Delhi Society of Haematology.

In collaboration with:

National Thalassemia Welfare Society, New Delhi.

Dr. A.K. Dutta

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 (M) 9810112656

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Organizing Secretary
 (M) 9811367371

Dr. Harish K. Pemde

Organizing Secretary

थैलासीमिया एण्ड सिकल सेल सोसायटी, इन्दौर

थैलासीमिया एण्ड सिकल सेल सोसायटी ऑफ इन्दौर व चोइथराम हॉस्पिटल रिसर्च सेन्टर के संयुक्त तत्वाधान में 14 नवम्बर को सातवां राष्ट्रीय थैलासीमिया दिवस मनाया गया। मुख्य अतिथि चोइथराम हॉस्पिटल के एम॰ डी॰ डॉ॰ कमलाकर वैद्य, विशेष अतिथि एम॰ एस॰ गोयल व डॉ॰ अशोक पोरवाल, डॉ॰ कामना जैन, डॉ॰ शिखर जैन, डॉ॰ मोहिनी हर्षे, डॉ॰ गोरीराव पासी थैलासीमिया सेन्टर की काले सिस्टर कार्यक्रम में उपस्थित थे। थैलासीमिया सोसाइटी की ओर से स्वागत उपाध्यक्ष मनोज पाहवा, संरक्षक लोकेश

खूबनानी, सचिव रमेश हर्षवाल एवं थैलासीमिया रोग से पीड़ित बच्चों अनुराग पाहवा और विश्वनाथ दवे, चेतन आदि बच्चों ने किया। चोइथराम रिसर्च सेन्टर की सिस्टरों द्वारा थैलासीमिया रोग के संबंध में एक प्रदर्शनी का आयोजन किया गया। जिसका उद्घाटन मुख्य अतिथि डॉ॰ कमलाकर वैद्य द्वारा किया। मुख्य अतिथि द्वारा थैलासीमिया से पीड़ित बच्चों को मिठाई, चाकलेट एवं गिफ्ट बच्चों को प्रदान की गई। संचालन सचिव रमेश हर्षवाल ने किया, आभार उपाध्यक्ष मनोज पाहवा द्वारा व्यक्त किया गया।

अजमेर रीजन थैलासीमिया वेलफेयर सोसायटी

16 नवम्बर अजमेर रीजन थैलासीमिया वेलफेयर सोसाइटी के तत्वाधान में थैलासीमिया रोग की रोकथाम व बचाव हेतु थैलासीमिया पखवाड़ा मनाया गया। उक्त पखवाड़े के दौरान अशोक कुमार सैन की अध्यक्षता में गठित समिति के द्वारा सम्पूर्ण संभाग के जिलों अजमेर, टोंक, नागौर, भीलवाड़ा में थैलासीमिया रोग की रोकथाम व बचाव हेतु सघन प्रचार व प्रसार किया गया साथ ही उक्त स्थानों पर थैलासीमिया रोग से पीड़ित बच्चों की जानकारी प्राप्त करते हुए उनको उपलब्ध करायी जाने वाली सुविधाओं का जायजा लिया गया।

ईश्वर पारवानी ने बताया कि पखवाड़े की कड़ी में थैलासीमिया बच्चों की ड्राईंग, डांसिंग व गायन प्रतियोगिता आयोजित की गई। ड्राईंग प्रतियोगिता में श्री विवेक प्रथम, कुमारी हिमाद्री द्वितीय तथा सुनील पंजाबी तृतीय विजेता रहे। इसी प्रकार गायन प्रतियोगिता में हिमाद्री सैन प्रथम, कृतिका गुप्ता द्वितीय तथा दीपिका तृतीय रही। डांसिंग प्रतियोगिता में श्री हितेश प्रथम, कुमारी हिमाद्री द्वितीय तथा कृतिका तृतीय रही। समस्त विजेता बच्चों को मुख्य अतिथि डॉ॰ अनुप तन्खा अतिरिक्त प्रधानाचार्य जवाहर लाल नेहरू आयुर्विज्ञान महाविद्यालय तथा डॉ॰ प्रभा सिंहल अधिका राजकीय जनाना चिकित्सालय द्वारा पुरस्कार वितरित किए गये तथा सभी थैलासीमिक बच्चों को डॉ॰ जितेन्द्र चौधरी के द्वारा सांत्वना पुरस्कार वितरित किए गये।

पारवानी के अनुसार थैलासीमिक पखवाड़े की कड़ी में थैलासीमिक बच्चों के चिकित्सा जाँच हेतु निःशुल्क चिकित्सा शिविर लगाया गया तथा थैलासीमिया रोग की रोकथाम व प्रभावी बचाव हेतु विचार गोष्ठी आयोजित की गई जिसमें डॉ॰ पुखराज गर्ग शिशु रोग विशेषज्ञ एवं डॉ॰ भरत छबलानी तथा श्याम सुन्दर शर्मा वरिष्ठ तकनिशियन द्वारा उक्त रोग पर व्याख्यान दिया गया तथा लगभग 100 बच्चों के स्वास्थ्य की गहन जांच की गई। पखवाड़े के अंतिम दिन साई बाबा मंदिर में विशिष्ट अतिथि डॉ॰ प्रभा सिंहल तथा अनुप तन्खा के नेतृत्व में बच्चों के अच्छे स्वास्थ्य हेतु प्रार्थना सभा आयोजित की गई जिसमें थैलासीमिक बच्चों के अभिभावकों ने भाग लिया। उक्त पखवाड़े को सफल बनाने हेतु सोसायटी के पदाधिकारी डॉ॰ प्रेम बी॰ चान्दवानी, अशोक सैन, मनोहर पंजाबी, जेठानन्द, अमित अग्रवाल व दिलीप, अजय भटनागर तथा आदर्श शिक्षण संस्थान के द्वारा तन मन धन से सहयोग प्रदान किया गया।

N.T.W.S.

Picnic

National Thalassemia Welfare Society organized a PICNIC for the 11th consecutive year on Sunday 1st February 2004 at APPU GHAR. Around 650 members enjoyed the free rides, ice games, hot water bath and DJ dance party. The APPU Ghar committee co-operated with us and kept the pace of the swings slow so that the children could enjoy alone without fear. About 100 Children from Rohtak Thalassemia society along with their parents also came to enjoy the Appu Ghar Picnic. The Thalassemic children were shouting with joy while enjoying the thrilling moments on the rides. Mr. Rakesh Babbar, Chairman, Mr. S.C. Malhotra, General Manager and Mr. Shameem deserve special appreciation for their co-operation.

New Air-conditioned Ward at DDUH

Thalassemia ward at DDUH has been shifted to a new 8-bedded cubicle. National Thalassemia Welfare Society has donated 2 A.Cs. and 1 colour T.V. to this ward. Now Thalassemics at DDU Hospital can "Enjoy" their blood transfusion in a congenial atmosphere. National Thalassemia Welfare Society is obliged to Mr. Anil Arora and Dr. Y.V. Verma of LG Electronics for Donating 2 Air Conditioners and Three Televisions.

Condolence

The executive of National Thalassemia Welfare Society expresses deepest grief & sorrow on the sad demise of **Dr. B. N. Dara on 17th Jan 2004.**

Dr B. N. Dara was a noted paediatrician from Jaipur settled in Delhi after his retirement had a Philanthropic nature. He had a special sympathy towards Thalassemic Children. He donated a handsome amount to our society to initiate an award to an Indian Doctor/Scientist for his exceptional work in the field of Thalassemia

His contribution helped us in honouring some of the outstanding Haematologists in India. Thalassemics owe a lot to the departed divine soul.

We pray the Almighty to rest the departed soul in peace & give courage to the bereaved family to bear this irreparable loss.

National Thalassemia Welfare Society

**Picnic at Appu Ghar, New Delhi
on 1st Feb., 2004**



Dr. Jitendra Choudhry, Chief Guest alongwith Mr. Iswar Parwani conferring the 2nd prize to Ms. Kavita Gupta in a Singing competition in Ajmer.



Thalassemics of Ajmer participating in Painting Competition.

TASWELS, Orissa

Introduction:

Rotarians, parents of patients, Doctors and elite citizens joined hands to form a society, Thalassemia and Sickle Cell Anaemia Welfare Society (TASWELS) on 3rd May 1998. The organisation is dedicated to help the children suffering from blood (Haemoglobin) disorders.

TASWEL has 182 life members and 15 patrons. Efforts are on to induct more life members, patrons, Institutions, and NRI's into the family. TASWEL has been fortunate enough to have Madam Susheela Rajendran, Lady Governor of Orissa as chief patron and also Mr. Pratip Kumar Mohanty, IAS Chief Secretary Orissa, Mr. Sudhansu Bhusan Mishra, IAS (Retd) and Mr. D.P. Bagchi, IAS (Retd) as Honorary Patrons.

The society maintains a Register of the patients who come for the treatment from different parts of the State. In the process it has registered about 330 patients.

Patients from far away places like Sambalpur, Bhrampur, Raygada, Deogarh, Dhenkanal, Mayurbhanj, Nayagarh etc have also registered

Activities 2002-03

Iron Chelation:

The Society for the first time in Orissa is providing iron Chelation Therapy with imported Infusion Pumps. It has 6 pumps in the pool. 96 injections have been given during the year. However, cost of Desferal injection makes it a difficult proposition for proper treatment. Donors are requested to sponsor patients, for the same.

Arrangement for Saline Washed Packed Cell:

Arrangement has been made with BMC Blood Bank to provide saline washed packed cell to Thalassemics on free of cost.

Supply of B.T. Set and Scalp Vein Set etc., for Transfusion

The registered patients are provided all materials required for blood transfusion, at a nominal cost.

Arranging Blood Donation Camps

The Society has been instrumental in arranging Blood donation camps for BMC Hospital Blood Bank, which provides blood to haematology patients without exchange

It deputes its representative to the donation camps and creates public awareness on Voluntary Blood Donation.

- a. The Society has been able to arrange 57 Blood Donation camps and have collected 1743 units of blood during the year.
- b. The Society provides Janata Accident Insurance Policy to all blood donors in Blood Donation Camps organised by them. It spent Rs.8663/- on 1925 donors.

Haematology OPD

Haematology consultant from S.C.B. Medical College along with his team examines and advises Thalassemia, Sickle Cell and other anaemia patients on every 1st Sunday at Haematology OPD organised by TASWELS at BMC Hospital. On TASWELS request the services has been placed by H & F.W Department at BMC Hospital.

Vaccination for Hepatitis-B

Vaccination programme was started in 1999. It has been expanded now.

Day Care, Diagnostic & Research Centre: (At Shishu Bhawan, Forest Park, BBSR)

The Government of Orissa has allotted a portion of Shishu Bhawan to the society. The centre was inaugurated on 22nd June 2003 for providing quality diagnostic and treatment facility to the Thalassemic & Sickle cell patients and general public.

Development Projects

Rotary Matching Grant Project

In collaboration with Rotary Club of Bhubaneswar and Rotary Club of Brighton, R.I. Distt 7120, USA, a Rotary Matching grant Project of US\$ 24850/- was forwarded to Rotary International. It has been sanctioned. This will help the society in a great way for accomplishment of its objectives towards community services.

Another project "is in the making". Centre for Genetic Counselling has been adopted by Rotary Club of Royal; BBSR. An assurance of US\$ 90911 + US\$ 6006 has been indicated by PDG of Rotary Club of Lords valley Dist 7410. The project cost is estimated at Rs.21.5 Lakhs

approximately. This will provide unique facility for diagnosis of Haemoglobinopathy.

Events during the year

- a. Society observed 14th November as National Thalassemia Day, and witnessed the following activities.
 - i. Rally of 300 school children.
 - ii. Inauguration of renovation work at Sishu Bhawan.
 - iii. Blood Donation Camps at BMC Hospital
- b. Mass awareness Camp at Meena Bazar, Utkal University Campus in collaboration with RMRC, Bhubaneswar sponsored by "Ananya" on 23rd Feb. 2003. 100 persons including students were screened.
- c. Training of 92 village level volunteers on first aid in collaboration with St. John ambulance & Rotary Club.
- d. Health check-up camp at Dhauli.
- e. Health awareness programme and counselling on a structured basis at Mainsikhal and Daspur with the assistance of St. John Ambulance.
- f. Preparation & Distribution of awareness Literature.
- g. On 24th Feb. 03, a seminar was organised at Blood Bank of BMC Hospital, Dr. R.P. Mishra delivered a talk on "Multiple Transfusion in Thalassemics".

Society's Benevolent Donors

- a. M/s. NALCO has donated a sum of Rs. 1,40,000/- to renovate Sishu Bhawan. The society acknowledges its gratitude to the company.
- b. Society is also grateful to Rotary Club, Kolkata, Green Park, for sparing Rs. 32,000/- for renovation of Shishu Bhawan.
- c. Society got an assistance of Rs. 1.00 Lakhs from Mahanadi Coal Fields, Orissa
- d. Society has also received several contributions from other Donors & Patrons.

Income Tax Exemption & F.C.R.A. Clearance

Income tax exemption under section 12A and 80G of Income Tax Act, 1961 for the year 2003-04 & 2004-05 has been granted to the Society. The society has mobilised Rs. 1,78,231/- during the financial year. We can also receive clearance from Govt of India through our registration under Foreign Contribution Regulation Act

1976, so that we receive funds from foreign funding agencies, service organisations & individuals Contribution and donors.

Vision

The Society looks at the future with optimism for providing better health service to community and aims at "Care until Cure and Control". To achieve above objectives, it has following vision.

1. To start a PRE-NATAL Diagnostic centre to conduct "Chorionic Villous Sampling" & Amniocentesis.
2. Basic & essential facilities of Thalassemics for which we have drawn the kind attention of both Central & State Governments. They are:
 - a. Thalassemics should be declared as physically handicapped.
 - b. Statistics of such patients through Census operation.
 - c. Free & regular blood supply to patients.
 - d. To wave of Local taxes on Life Saving and essential medicines.
 - e. To make "Kelfer" available in our State.
 - f. Diagnostic facilities in three medical colleges/district Head Quarter Hospitals and health centres.
3. To establish a Blood Bank of our own (society)
4. There will be a continuous programme of population screening/awareness activities and genetic counselling for prevention of Thalassemics.
5. To have 5 acres of land to establish a 125 bedded State of the art children hospital with 25-bed ward for haemolytic anaemia patients.
6. To expand the activities to other parts of the State in phases.

Report from Amritsar

Amritsar Thalassemia Welfare Society organized a lecture on Management and concepts of Thalassemia by Dr V.P. Choudhry, Prof & Head of Deptt. of Haematology, AIIMS New Delhi on 1st November 2003. The lecture was attended by Principal, Vice-Principal, Heads of Deptts of Govt. Medical College and Hospital, Amritsar, Medical students and parents of Thalassemia patients.

2nd day, Dr. V.P Choudhry examined Thalassemia patients and advised them for their proper care & treatment.

अपील !

निवेदन है कि मेरा नाम संगीता है। मेरी उम्र 18 साल है। मैं थैलासीमिया नामक रोग से ग्रस्त हूँ। इसका ईलाज हर 15 दिन बाद खून चढ़वाना जोकि कलावती सरन बाल चिकित्सालय से 18 साल से चढ़ा रही हूँ। मैं 6 महीने की उम्र से ही कलावती अस्पताल से खून चढ़वा रही हूँ। मेरे माता-पिता का स्वर्गवास हो चुका है। हम चार बहन-भाई हैं। हम दादा-दादी के पास रहते हैं। दादा जी वृद्धावस्था होने के कारण कुछ कमाने योग्य नहीं हैं और मेरे भाई भी अभी छोटे हैं। इस कारण हमारा घर का खर्च बहुत मुश्किल से चल पाता है। और घर के खर्च के साथ मेरी बीमारी में काफी पैसा खर्च हो जाता है। इस बीमारी के साथ-साथ मुझे एक और बीमारी की शिकायत है जिसका नाम हैपेटाइटिस-सी है। इस बीमारी का कारण है बार-बार खून चढ़ना। इस का ईलाज है हैपेटाइटिस-सी के इंजेक्शन जोकि काफी खर्चीला है

करीबन 90 हजार जोकि मैं कराने में असमर्थ हूँ। इसलिए मेरी आप से प्रार्थना है कि आप मेरी कुछ मदद करें। आप की अति कृपा होगी।

धन्यवाद।

संगीता भोला

17 तिलक खण्ड, गिरि नगर, कालकाजी, नई दिल्ली-19

Sangeeta is getting free transfusion and chelation from Kalawati saran Hospital. NTWS is also helping her with free filters and Rs. 500 per month.

Those who wish to help her for her treatment of Hepatitis-C are requested to send the cheques in favour of "National Thalassemia Welfare Society" with a note "for Sangeeta" on back of the cheque or by cash against receipt from the Society.

Dr J. S. Arora

National Thalassemia Welfare Society (Regd.)

KG-1/97, Vikas Puri, New Delhi-110 018 Tel: 55491151, 25511795

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

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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: 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

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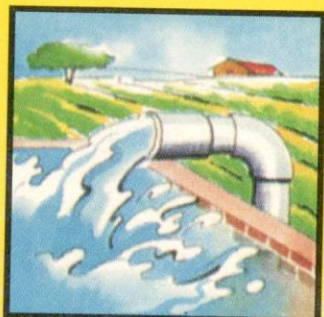
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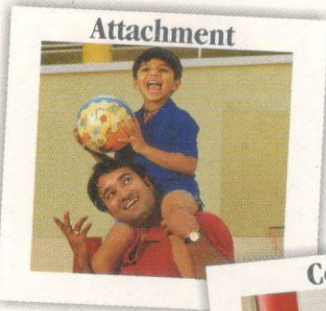


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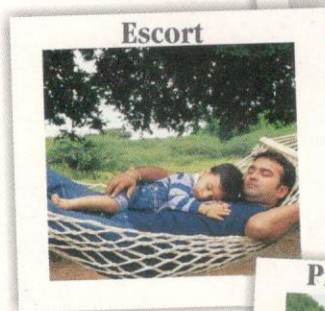
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Attachment



Confidence



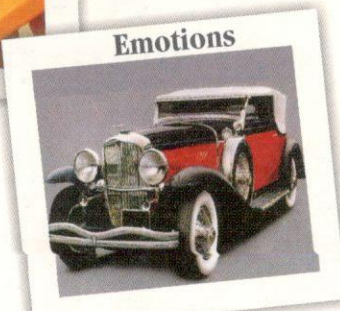
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