SHC INDIA VOICE

SOCIETY FOR HEMOPHILIA CARE NEWSLETTER

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INSIDE THIS ISSUE

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"Nobody should die or become disabled when the treatment is available"

Jittender Kapoor

Yes! This is SHC India Vision and this Newsletter a Voice to it.

While pursuing our vision we are happy to take yet another initiative in furthering our cause. This issue of "SHC India Voice" is the first one and would be a source of information; a platform to debate; an advocacy tool; and the mouth piece of SHC India & its partners.

It is important to mention in this inaugural issue that SHC India supports the needs of people suffering from Hemophilia; other Bleeding Disorders; HIV/AIDS and Hepatitis. Our consistent focus is on "AART" i.e. **A**wareness, **A**dvocacy, **R**ehabilitation and **T**raining/ Research concerning Hemophilia in the country.

SHC India was founded on October 10, 2005 to strengthen the hemophilia movement. Since then, we have been working consistently towards the goal of achieving optimum Hemophilia Care. It is an all India public funded charity registered under various Govt. Acts and run by a group of professionally qualified & experienced people. It operates in the States of Delhi, Haryana, J & K, Punjab, U.P., Bihar, Karnataka and Kerala. We believe & practice in the highest order of professionalism, accountability and transparency.

We seek public investments rather than donations so that we can provide returns through total accountability & transparency to the investors.

We wish to record our gratitude to the Govt. of Delhi, Haryana, Bihar, U.P., Karnataka for recognizing Hemophilia & initiating Hemophilia Care with free Factors in their hospitals.

We hope you would analyze our maiden effort and respond back with suggestions in improving it and raising voice for furthering the cause.

Have a nice & thought-provoking reading!

Yours in service

Jittender Kapoor
Chairman, SHC India

SHC India Logo

SHC India logo is based on the philosophy of leading together a healthy life, free of bleeds. People with bleeding disorders (the person depicted in white) are supported by healthy persons (the person depicted in red). This concept is adopted by most of the NGOs working for the cause of hemophilia world wide so that there is uniformity in recognition. The SHC India logo shows a drop of blood depicting that the cause is related to precious Blood. The two children (in red & white) together reflect supportiveness & basic human value of living together irrespective of caste, creed & colour.

Hemophilia *is a rare, inherited bleeding disorder due to which a person's blood doesn't clot normally. A person having hemophilia may bleed for a longer time than others after an injury. The person may also bleed internally, especially in his knees, ankles, hips and elbows. This bleeding can damage joints or muscles and may sometimes be fatal. People are born with hemophilia and have little or no clotting protein needed for normal blood clotting. These proteins are called the Clotting Factors.*

A person with hemophilia can lead a near normal life if he receives timely and adequate treatment including medicine called Anti Hemophilia Factor (AHF). Since it is a human-blood or recombinant product it is very expensive and unaffordable even for a rich family.

In India there should be more than 3,00,000 families living with hemophilia directly and indirectly.

“Sky is not going to fall”

“Sky is not going to fall”

This is what the Principal cum Dean of GSVM Medical College, Kanpur said when SHC India representative met him in his office. He was quite indifferent and unwilling to listen about the problems hundreds of PwHs are facing there.

It may be recalled that earlier this year High Court of U.P. recognised the genuine needs of thousands of PwHs in U.P. and issued orders to the Govt. of U.P. to make life saving treatment available to the hemophilia affected population in U.P. immediately.

Hats off to the extra-ordinary efforts made by Hemophilia Societies working in U.P. who took up this daunting task of filing a PIL. In response the Govt. of U.P. took a positive action and allocated an annual budget of Rs.23.00 Crores approx. for FY 2009-10 to U.P. Medical Colleges/Hospitals for procurement of life saving medicines to be given free to the affected population in their hospitals.

Progress in utilisation of Funds allocated (In Crores)

Sl.	Name of Institute	Funds released	Funds Utilised	% of Funds Utilised
1.	Agra, SNMC & Aligarh	1.06	0.19	18%
2.	Allahabad, KNMC	0.21	0.21	100%
3.	Gorakhpur	1.83	0	Funds returned
4.	Kanpur, GSVM	3.77	0.33	9%
5.	Lucknow, SGPGI	2.20	0.84	38%
6.	Lucknow, CSMMU	0.22	0.22	100%
7.	Varanasi, BHU	1.04	0.56	54%
	TOTAL	**10.33**	**2.35**	**23%**

However, several of these colleges have shown least interest in procurement, in adopting a uniform treatment protocol and safety norms while procuring Factors. Most of the Medical Colleges are not procuring Anti Hemophilia Factors for one reason or the other. The result is that patients have to move from pillar to post with no treatment. This is most unfortunate especially when money is no issue.

For example in Medical College, Kanpur, the Principal has formed a committee of 3 doctors who have to meet every time just to decide if Factor Injection is required or not and this process (a unique one in the world) takes 3 to 4 days for each patient. The patient himself or his attendants have to pursue these 3 doctors before any action is taken. Ironically 2 of these doctors are from his own Orthopaedic department whereas hemophilia is a hematological condition.

Needless to say that there is a practice followed internationally that a hemophilia patient when bleeding should be given immediate & adequate Factor Infusions. The Principal (a Bone Specialist) says “Don’t teach me; I know my job well”. He does not want to recognise that a Patient & his family who live day & night with a chronic ailment like hemophilia know equally well, if not better, whether he is bleeding or not.

Moreover, doctors send patients back untreated & without writing anything on the prescription to escape any action.

Though the Govt. has provided the money yet the deciding authorities in these Medical Colleges do not follow the treatment protocols and financial appropriateness. Obviously there are some vested interests who are playing with the lives of patients.

Patients want transparency, accountability, fast decisions and with their involvement.

Satya (name changed as he fears for harassment) when asked what problem he faces, he said, “The Medical Officer at the Hemophilia Treatment Room/centre is the best person to decide about the need of Factor Infusion & its quantity. But he is helpless as he has to wait for other 2 doctors to sign on the prescription before infusion can be given.”

Other patient, who had to wait for 5 days before he was actually infused with Factors, said “The bleeding patient is in terrible pain. He should be given immediate Factor infusion & in adequate quantities before any further investigation may be done. Waiting for hours & days would damage his joint/muscle & the treatment for the same would be 4 to 5 times more expensive. Also the damage to his joints & muscles is irreversible.

“Most of the time Factors are in short supply”, said Sandeep (name changed). “Why can’t adequate quantities of Factors (Anti Hemophilia Factors come under Life Saving Drugs in the WHO & DCGI Drug List) be stocked so that patients do not suffer because of non-availability of Factors”.

Factor procurement in GSVM Medical College, Kanpur is dismal at just 9%.

25 year old son of Shanno Devi (name changed) who has contracted HIV from infected & unscreened Cryoppt infusions is fighting a lone battle with hemophilia as well as HIV. Said, “Since Govt. has been kind enough to help us, why can’t the best quality Factors be used”.

With these sufferings if the Sky falls, the doctors like Principal, GSVM Medical College, Kanpur are least bothered.

AHF selection –
a big safety concern for patients

Some people are trying to compromise on the safety issues of life saving medicine called AHF for people suffering from hemophilia. There have been efforts where a second grade product, which has not undergone any clinical trials, is being forced upon the innocent children thereby exposing them to yet more life threatening situations. The quality of AHF is substandard. Sometimes there is some problem in its resolution due to which there is lot of wastage & sometimes the PwHs suffer life threatening reactions. This is not efficacious and practically costs more to the exchequer.

SHC India has taken this issue with the Govt. Authorities and we are gravely concerned about it. We hope this concern will receive the highest priority before any further damage is done to the innocent patients especially children.

It is pertinent here to mention that earlier usage of low quality Factors have led to fatal infections to those who were exposed to such blood products. More & more PwHs are detected to have contracted fatal viral infections and now they are not fighting with hemophilia alone but with these added fatal infections.

We request the Medical Institutions/ Hospitals not to ignore the safety aspects as it is not a cost effective process in the long run.

Maiden Hemophilia Seminar in Kashmir

Hemophilia Seminar in Kashmir

Venue: Govt. Medical College, Srinagar
Organisers: SHC India
& Govt. Medical College, Srinagar

Kashmir- known as “Paradise on Earth” by some & “Switzerland of Asia” by others.

People are quite humble & emotional. But they lag behind even in the basic health care facilities. “Right to Life” provided by our Constitution has been trashed by the decision makers & politicians there like in many other States of India. The militancy has put breaks on the development tempo especially in the health sector.

However, the situation is fast improving.

SHC India took a step forward to contribute to improving the quality of life of persons suffering from hemophilia when it organized a maiden seminar on hemophilia on July 29, 2009. Thanks to the Dr. (Mrs.) S. Mir, Principal, Govt. Medical College, Srinagar & Dr. M. I. Quadri, Head of Deptt. of Transfusion Medicine & Hematology for taking interest in this direction.

The seminar was inaugurated by Shri R.S. Chib, J&K Minister for Medical Education, Sports & Youth Affairs. There were about 300 delegates who had come from Govt. Medical College Hospital, Jammu, SKIMS, Srinagar, JV Medical College Hospital, Srinagar, G.B.Pant Paediatric Hospital, Srinagar and doctors from various departments of Govt. Medical College, Srinagar besides the PG medical students.

There were more than 45 PwHs who had come along with their families from various parts of Kashmir to attend to interactive session with Hemophilia Specialists.

SHC India was represented by its Chairman, Shri. Jittender Kapoor & Executive Director, Shri Vijay Kaul & Dr. Mukhtar Masoodi.

Faculty from outside J&K comprised of Dr. Pravas Mishra, Deptt. Of Hematology, AIIMS, New Delhi & Dr. Madhumita Chowdhary, Deptt. of Genetics, AIIMS, New Delhi besides local faculty from SKIMS, GMC, Srinagar & Jammu and Bone & Joint Hospital, Barzulla.

The important issues were diagnosis, disability due to lack of treatment & safety of treatment. J&K Hospitals are using FFP & Cryo for PwHs as Factor Concentrates- life saving drugs are not available in any of the J&K Govt. hospitals and there is an increase in number of fatal infections.

Shri R.S. Chib, Hon’ble J&K Minister for Medical Education addressing the delegates

The outcome of the seminar was loud and clear and that J&K should have the following facilities at the earliest possible:

1. Setting up of Hemophilia Care Centres in major districts like Jammu, Srinagar, Anantnag, Baramulla, Rajouri, Akhnoor etc.

Contd. on page 4

Mother of 2 sons (both with hemophilia) sharing her pain & agony with delegates

2. Setting up of diagnosis in Jammu & Srinagar.
3. Procurement of life saving medicines i.e. AHF by the Government for free treatment of PwHs of the State.

Hon'ble Minister Shri R.S. Chib declared in his inaugural speech that all these concerns especially on availability of medicines will be positively looked into very soon.

Dr. Pravas Mishra, Hematologist, AIIMS, New Delhi in interactive session with PwHs

It may be recalled that SHC India has already initiated a similar advocacy campaign in Jammu earlier this year with the Secretary General, Indian Red Cross, Jammu Chapter taking keen interest under the Chairmanship of Divisional Commissioner, Jammu.

Let us hope these initiatives bring fruits & smiles on the faces of hundreds of families affected by hemophilia in J & K State.

PwHs: Acronym for "Persons with Hemophilia"

LET US SAVE DAL LAKE
BECAUSE WE CAN

Trivia Quiz

i. The human body has ______ chromosomes.
ii. Hemoglobin is the blood protein that carries ________.
iii. A physician who specializes in the disorders of blood is called a ____________.
iv. The full form of H.I.V. is ______________________.
v. Hepatitis is an inflammation of the ______
vi. The process by which the body stops bleeding is termed as ______________.

ANSWERS : i. 23 pairs, ii. Oxygen, iii. Hematologist, iv. Human Immunodeficiency Virus, v. Liver, vi. Hemostasis

SHC India announces treatment support for PwHs

"PATH"

Providing Affordable Treatment for Hemophilia

The support under PATH will be provided for meeting the treatment cost in connection with hemophilia.

The support is limited to Rs.10,000/- in a year.

The eligibility criteria is as under:

1. The child should be below 14 years of age.
2. Child should be a regular student in a school
3. Family Income should be below Rs.50,000 annually.
4. The family should not be residing in States of Delhi, Haryana, U.P., Bihar, Karantaka, Tamil Nadu & Puducherry as these States provide free Factors to all people suffering from Hemophilia.

The needy persons may apply on a plain paper to:

Society for Hemophilia Care,
129, Amberhai, Opp. Church,
Sector-19, Dwarka,
New Delhi-110075

& send it alongwith enclosures by post/courier in the below given form:

Request for Hemophilia Treatment Support

1. Name of the Child:
2. Factor & Deficiency level:
   (enclose certificate of diagnosis)
3. Date of Birth:
4. Class in which studying:
5. Name of the School where studying:
   (enclose certificate from the school)
6. Yearly Income of the family: Rs.
7. Complete Address:
   (enclose proof)
8. Name of the State:

If you have the fighting spirit Hemophilia can be your strength

SHC India in action

SHC India Mission is AART – Awareness; Advocacy; Rehabilitation; and Training & Research. In persuasion of this, some of our Mission Activities during the last 6 months are:

Training cum Hemophilia Awareness film **"A Journey with Hemophilia"** was produced and shown to the target groups like people affected by hemophilia, their families, social workers, nurses and psychologists/ doctors at various places. This film is a powerful audio-visual tool. Our endeavour was to have very important issues raised through this film and communicating effectively with the sufferers, the treaters & decision makers.

This film is based on Research & included survey conducted with Persons affected with hemophilia, their parents, psycho-social workers, para-medicos & medicos. Those interested in having a copy can write to us at admin@shcindia.org

Film: A Journey with Hemophilia

Focus Group Discussion with PwHs in Varanasi

Focus Group Discussions with various stake holders in New Delhi, U.P., Bihar, Rajasthan & Haryana were organized and Survey conducted.

Awareness on hemophilia among the psychosocial workers/ students in various States of India. Hemophilia is the least known disease and even the doctors lack skills & basic knowledge of treatment protocols recognized globally for hemophilia care.

Advocacy & PR initiatives taken by Hemophilia Society of Bihar are yielding results. Renowned Film Icon Hema Malini donated Rs.14.00 Lakhs to the Hemophilia Hospital, Patna for its further upgradation.

SHC India delegation meets Shri J.P. Singh, Pr. Health Secretary, Govt. of Delhi

Hemophilia treatment in the 3 Delhi Govt. Hospitals is still in its preliminary stage. We thank Shri J.P. Singh, Pr. Health Secretary, Govt. of Delhi who listened to the delegation for various problems being faced by PwHs. He assured pro-active steps for improving the same. Results are already positive.

World Hemophilia Day was celebrated on April 17 2009 at DDU Hospital, New Delhi. A 2 hour hemophilia CME was also held on this occasion. PwHs and their families participated in huge numbers.

Dr. R. Pathak, Nodal Officer, Hemophilia, DDU Hospital being greeted on WHD 2009

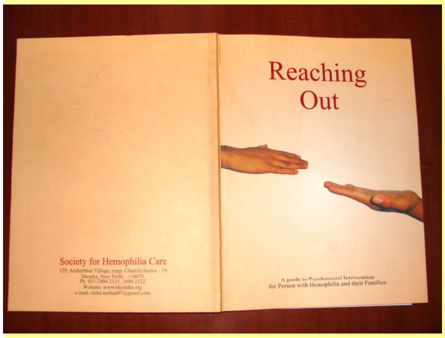
Painting Competition organized for Children with hemophilia as a part of the World Hemophilia Day 2009. Children drew through their imagination on Fauna & Flora. Surprisingly none drew anything related to hemophilia.

Winners of the painting Competition as a prelude to WHD 2009

The well researched **Training Programme** for psychosocial Workers in hemophilia was developed. Training Programmes conducted for building capacities of treaters & counselors so that quality of life gets improved amongst the affected people under the leadership of Richa Mohan.

Training Programme at BHU, Varanasi

Training Manual titled **"Reaching Out"** A guide to psychosocial Intervention for person with Hemophilia and their families was published and distributed among the participants as well as hemophilia societies. Those interested in receiving the free copy may write to us at admin@shcindia.org



Training Manual "Reaching Out"

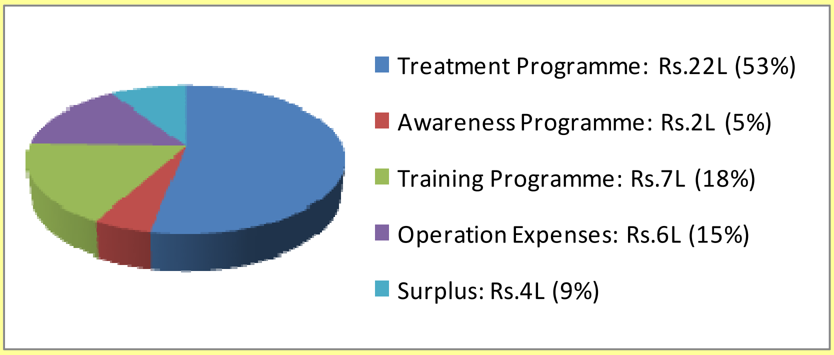
About 400 Psychosocial professionals acquired information, knowledge and skills; so that they can support person with hemophilia in their institutions/ hospitals.

Based on the baseline survey, Training programmes were developed and Training imparted to doctors, nurse & PSS workers in various States.

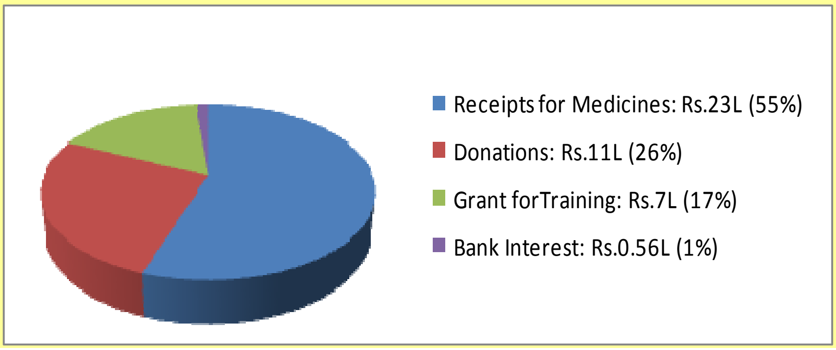
Workshop with Doctors & Nurses in PMC, Patna

Wagon Wheel of SHC India Balance Sheet 2008-09

Expenditure



Income



Thank you Supporters

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Let us play doctor doctor

Kanu: Hi everybody! We are 4 friends and can play doctor doctor. Do you all agree?

Piyush: Yes, that should be exciting & interesting

Deepu: Yes, I too am ready.

Dolly: But I will act as a doctor.

Kanu: Don't worry. I will be Mummy, Deepu will be my son & Dolly a doctor. And Piyush the Papa.

in makeshift doctor's room……………………..

Kanu: Doctor doctor, my son Deepu has a swollen knee and the swelling is increasing. Please help us.

Dolly: Don't worry. He must have been hit by something hard.

Kanu: But Madam he has hemophilia.

Dolly: So what. Buy Iodine Ointment & massage it on his knee for 2 to 3 days. The swelling will go. Also don't forget to give him Asprin three times a day for 3 days.

Piyush: Oh my God. This doctor does not know that massage will increase Deepu's bleeding and damage his joint as well. Asprin will prolong bleeding.

Kanu: Madam, massage & asprin are not advised in hemophilia bleeds.

Dolly: Don't teach me. I am the doctor; not you. Do what I say , otherwise go away.

Kanu & Piyush: Deepu beta, let us go to some other doctor.

(Note: Hemophilia is a rare condition & not many doctors come across such children. And not many doctors know about its management. There is nothing wrong if you say that you don't know about how to treat bleeds in hemophilia. Certainly nobody can know everything.

SHC India can assist you in acquiring the necessary skills & training to be a Hemophilia treatment expert. If interested, please do write to us at admin@shcindia.org

(SEND IN YOUR REAL LIFE STORIES. WE WILL PUBLISH THEM HERE)

SHC India is a public funded charity and works with complete transparency, work ethics and accountability towards its donors and other partners through qualitative management and effective communication. It also encourages an environment under which the public has the opportunity to analyze the result of their support. We believe that a donor invests for social returns in making a quality change in the lives of the most needy.

"Hemophilia care is within reach regardless of ability to pay, and we promise to accomplish it in complete transparency with our donors and affected community.

Thousands of children suffering from hemophilia spend most of their time on bed. They also miss their schools. Sadly their parents cannot afford their treatment…

You can make a positive difference in their lives by...

Donating to the below projects. A small portion of your annual income can gift life to a child - a life the child surely deserves!

- **Providing affordable treatment for hemophilia (PATH)**
- **Save a child having hemophilia (SAVE)**
- **Train and educate a child having hemophilia (TEACH)**

www.shcindia.org

Donating your spare time to the SHC INDIA

Contributing through your professional experience.

(donations are exempted from Income tax u/s 80G)

COMMITMENT FORM

I wish to make a donation of

Rs. 2000/-	Rs. 1500/-	Rs. 1000/-	Rs._________
for PATH	for SAVE	for TEACH	(tick appropriate)

Please find enclosed Cheque/D.D. No._____________________ for Rs_________

in favour of Society for Hemophilia Care, New Delhi. & send it to us at:

SHC India

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