



# Government of West Bengal. Directorate of Health Services (N.C.D. Section). Swasthya Saathi, Swasthya Bhawan Campus. Ground Floor, GN-29, Sector-V, Salt Lake, Kolkata-700091. Phone No.:- 033-23330212/118, Email ID:wbshfws@gmail.com.

Memo No. HWF-270225/18/2019/NCD-SEC/Thal/399

Date: 23 10 2019

#### ORDER

Administrative approval is hereby accorded for rolling out of the activity "Haemophilia Control Programme in West Bengal" under the National Programme "Haemoglobinopathies Control Programme" of NHM in entire state with effect <u>from 1<sup>st</sup></u>. <u>November '2019</u>. This has the approval under ROP (2019-20). All the facility in charges are requested to own this programme & make necessary arrangement by creating awareness & sensitization amongst all MO & staff & also to make this programme visible through IEC, Display of Signage in the facility. All Directors/Principals& CMOHs are requested for taking necessary steps for its wide circulation amongst all Health Care Providers.

#### Details are as follows:

- 1. State Nodal Centre: IHTM, Medical College, Kolkata.
- 2. State Technical Expert: Prof.(Dr) Maitreyee Bhattacharyya.
- 3. State Nodal Centre: State NCD Cell, Swasthya Bhavan.
- 4. State Nodal Officer:- Jt. DHS(NCD).
- 5. Facilities included All Thalassaemia Control Units (34).

J. Faci	List of TCUs.						
Sl.no	I.no List of the Facility Name of the District/ Health District						
1	IHTM, MCH, Kolkata (Nodal Centre)						
2	NRS MCH, Kolkata(Nodal Centre)						
3	National Medical College & Hospital	Kolkata					
4	R.G. Kar Medical College & Hospital	Komata					
5	IPGME&R- SSKM Hospital						
6	School of Tropical Medicine						
7	Burdwan Medical College & Hospital	Purba Burdwan					
8	Kalna SDH	Taiba barawan					
9	Bankura Sammilani MCH	Bankura					
10	North Bengal Medical College & Hospital	Darjeeling					
11	Malda Medical College & Hospital	Malda					
12	Murshidabad Medical College & Hospital	Mursidabad					
13	Jangipur SDH						
14	Jalpaiguri District Hospital	Jalpaiguri					
15	Coochbehar Govt. MCH	Coochbehar					



Sl.no	List of the Facility	Name of the District/ Health District
16	Balurghat District Hospital, D. Dinajpur	Dakshin Dinajpur
17	Nadia District Hospital, Krishnanagar	Nedia
18	Ranaghat SDH	Nadia
19	Tamluk District Hospital,	Purba Medinipur
20	Purulia Govt. MCH	Purulia
21	Suri District Hospital, Birbhum	Birbhum
22	Imambara District Hospital, Hooghly	Hooghly
23	Diamond Harbour Govt. MCH	DH HD
24	Uluberia Sub-Division Hospital, Howrah	Howrah -
25	Barasat District Hospital	N24P
26	Alipurduar District Hospital	Alipurduar
27	Raiganj Govt. Medical College & Hospital	Uttar Dinajpur
28	Basirhat District Hospital	Basirhat HD
29	Contai Sub-Division Hospital	Purba Medinipur
30	Kharagpur Sub-Division Hospital	Paschim Medinipur
31	Bishnupur District Hospital	Bishnupur HD
32	Asansol District Hospital	Paschim Burdwan
33	Kalimpong District Hospital	Kalingpong
34	Bauripur SSH	S24P

- 6. Checklist for each centre before starting the program:
  - A. Staff: for the TCU.(Medical Officer, Lab Technician, Counsellor, Staff Nurse & DEO).
  - B. Equipments: for the TCU. In addition one Semi auto coalgulometer will be supplied to 26 TCU facilities where not available.

sl.no	Name of TCU Facilities. Availability of Auto/Semi Auto Coagulomet			
1	Burdwan Medical College & Hospital	Not-Available		
2	Bankura Sammilani MCH	Not-Available		
3	Malda Medical College & Hospital	Not-Available		
4	Murshidabad Medical College & Hospital	Not-Available		
5	Jalpaiguri District Hospital	Not-Available		
6	Balurghat District Hospital, D. Dinajpur	Not-Available		
7	Nadia District Hospital, Krishnanagar	Not-Available		
8	Tamluk District Hospital,	Not-Available		
9	Purulia MCH	Not-Available		
10	Suri District Hospital, Birbhum	Not-Available		
11	Imambara District Hospital, Hooghly	Not-Available		
12	Diamond Harbour MCH	Not-Available		
13	Uluberia Sub-Division Hospital, Howrah	Not-Available		
14	Barasat District Hospital	Not-Available		
15	Alipuduar DH	Not-Available		
16	Raiganj MCH	Not-Available		
17	Jangipur SDH	Not-Available		
18	Bishnupur DH	Not-Available		
19	Contai SDH	Not-Available Not-Available		
20	Basirhat DH	Not-Available		
21	Kalingpog DH	Not-Available		
22	Asansol DH	Not-Available		

sl.no	Name of TCU Facilities.	Availability of Auto/Semi Auto Coagulometer
23	Kalna SDH	Not-Available Not-Available
24	Ranaghat SDH	Not-Available
25	Kharagpore SDH	Not-Available
26	Baruipur SDH	Not-Available

- C. Training of the involved HR:
  - For MO: 2 days training. Completed at IHTM. i.
  - ii. For lab technicians: 2 days training. Completed at IHTM.
  - For Counsellor: 2 days training. Will be taken up in due course. iii.
  - For Data entry operator: on site training when dedicated soft ware is developed. iv.
  - One session Sensitization trg.: for all MOs of the facility, Physicians, Paediatricinas & who are ٧. involved for Emergency Duties. This trg will be imparted locally by the trained MO & DY. CMOH-II. SOP will be shared.
- 7. State SOP: Already approved & available.
- 8. Implementation guideline:
  - a. In all TCUs Thalasseamia OPD will be hence forth designated as "Thalassaemia & Haemophilia OPD". For this necessary signage & IEC to be displayed in the facility to increase the visibility.
  - b. Any haemophilia patient attending OPD will first go to the counsellor for recording detail of the patient in the Patient wise Case Record Sheet . There after the patient will have go to the MO (trained) with the file, he/ she will examine the patient & advise ( all important findings to be recorded in the Patient wise Case Record Sheet). All Patients will be asked to attend OPD every 2 months normally & or immediately for emergencies.
  - c. Physiotherapy to be arranged during one of this visit & patient will practice it at home.
  - d. In case of active bleeding, Patient can attend TCU (Office hours), Emergency (non OPD hours) to get factor administered as per protocol.
  - e. Provision of factor from ER & a guideline of how much factor to be given to be kept/ displayed in ER prominently.
  - f. All patients will be provided with "Identity Card with Unique ID" & a patient wise diary where doctor will record the site of bleed & how much factor was given each time. Later on when the patient will attend at OPD, counsellor will record everything in the existing Case Record file from the available OPD/Emergency/IPD tickets or the patient wise Diary.
  - g. Patients will be sent to IHTM once in a year normally for examination, evaluation & further advice.
  - h. HBsAg/HCV/HIV to be tested every year.
  - Inhibitor to be tested every year.
  - X-ray of affected joint to be done once in a year. j.
  - k. Updated file to be sent to Data Entry Operator for entry in the software in real time when it is ready.
- 9. Procurement of Factors will be assessed by the Facility In charges & will arrange for procurement of Factors for three months requirement at a time through SMIS as the items have CMS approved vendors.
- 10. All patients will be registered at any of the available listed facility (34) for continuum care and management according to their convenience& choice. Entire exercise of initial registration will be completed by 31st. October'2019. Fund for procurement of Factors will depend entirely upon the facility wise case load and will be made available to start with from NHM & if any shortfall from state Budget.
- 11. All registered patients will be issued with an Identity Card by the head of the facility. These Identity Cards will be supplied from the state HQ in due course.
- 12. Prophylaxis administration of the factors will be restricted for patients up to the age of 10 yrs completed strictly.
- 13. All registered patients will be supplied with a patient wise Note Book with mentioning of the name, ID. No, Name of the Facility, Detailed address, mobile no. etc. (Plain paper binding exercise book of half of the A/4 size) by local purchase for recording of the care & management details chronologically.



- 14. A patient wise CASE RECORD will be prepared and maintained at the facility, where the initial patient record & chronological care & management details will be recorded as follow up for future use. The same will be printed from the state HQ & will be supplied to the Units. The additional sheets will have to be added locally for follow up as & when necessary.
- 15. Dy. CMOH-II of the district / health districts are already the District Nodal Officer for National Haemoglobinopathies Control Programme. They will take all steps for effect implementation of this programme under supervision of the Chief Medical Officer of Health keeping close liaison with the MCH situated in the district HQs.
- 16. The Directors, Principals & MSVPS will take necessary steps so that the programme runs effectively at MCHs. Dy. Supdts, who are entrusted with looking after the day to day activities of the TCUs will also look after this component of the Haemoglobinopathies control programme.
- 17. There is no provision for any recurring funding for this programme under NHM apart from cost for procurement of Factors. All the day to day expenditures if any incurred to be met locally either from available Thalassaemia Control Programme fund or from any suitable state Govt. fund of the facility.
- 18. Each of the facility needs to submit a monthly report in a prescribed format by 5<sup>th</sup>. of next calendar month. The format will be supplied from state HQ in due course.

All concerned are informed for necessary action.

#### Enclosed:- A copy of the State SOP.

Date: 23/10/2019

## Memo No. HWF-270225/18/2019/NCD-SEC/Thal/399

Copy forwarded for information & necessary action to the:

- 1. Director of Medical Education, Deptt. of H&FW, Govt. of West Bengal, Swasthya Bhavan.
- 2. Director of Health Services, Deptt. of H&FW, Govt. of West Bengal, Swasthya Bhavan.
- 3. Advisor, H & FW Department, GoWB, Swasthya Bhavan.
- 4. AMD(NHM) & Jt. Secy, Deptt. of H&FW, Govt. of West Bengal, Swasthya Saathi.
- 5. Additional Sectary (D & E), H&FW Department.
- 6. Managing Director, WBMSCL & Commissioner, H&FW Department.
- 7. Director, Institute of H & FW, Swasthya Bhawan.
- 8. Joint Secretary (PHP/MS Branch) Dept. of Health & FW, Govt. of West Bengal
- 9. Deputy Secretary (HS/PHP/MS Branch) Dept. of Health & FW, Govt. of West Bengal.
- 10. Sr. PS to Additional Chief Secretary, H& FW Department.
- 11. Director (Finance), State FMG, NHM, Govt. of West Bengal.
- 12. Programme Officer-I, NHM, Deptt. of H&FW, Govt. of West Bengal, Swasthya Saathi.
- 13. Programme Officer-II, NHM, Deptt. of H&FW, Govt. of West Bengal, Swasthya Saathi.
- 14. Financial Advisor, H&FW Department.
- 15. Financial Advisor, WB SH & FW Samiti.
- 16. Sr. Accounts of Officer, NHM. Govt. of West Bengal.
- 17. Addl. DHS (Admn), Dept. of Health & FW, Govt. of West Bengal.
- 18. Jt. DHS (NCD), Dept. of Health & FW, Govt. of West Bengal
- 19. Jt. DHS & SFWO, Dept. of Health & FW, Govt. of West Bengal
- 20. Jt. DHS (TB) & STO, Dept. of Health & FW, Govt. of West Bengal
- 21. Jt. DHS (PH & CD), Dept. of Health & FW, Govt. of West Bengal.
- 22. DDHS (Admin), Dept. of Health & FW, Govt. of West Bengal
- 23. DDHS(HA), Dept. of Health & FW, Govt. of West Bengal
- 24. DDHS (NCD-I), Dept. of Health & FW, Govt. of West Bengal
- 25. DDHS (NCD-II), Dept. of Health & FW, Govt. of West Bengal.

- 26. DDHS( Malaraia), Dept. of Health & FW, Govt. of West Bengal
- 27. DDHS(Leprosy) & SLO, ADHS (FS), Dept. of Health & FW, Govt. of West Bengal
- 28. ADHS, NCD-II, Dept. of Health & FW, Govt. of West Bengal
- 29. ADHS (Ophth.), Dept. of Health & FW, Govt. of West Bengal
- 30. ADHS (Mental), Dept. of Health & FW, Govt. of West Bengal
- 31. ADHS (Dental), Dept. of Health & FW, Govt. of West Bengal
- 32. ADHS (MPHWS), Dept. of Health & FW, Govt. of West Bengal
- 33. ADHS (FS), Dept. of Health & FW, Govt. of West Bengal
- 34. System Coordinator, IT Cell, Swasthya Bhawan with a request to upload this circular in Departmental Website.
- 35. Director, IPGMER/STM, Kolkata.
- 36. Principal.....(all MCH)
- 37. MSVP.....(all MCH)
- 38. Prof. (Dr.) Maitreyee Bhattacharyya, Director IHTM & Nodal Officer, Thalassaemia Control Unit, Medical
- 39. Prof. (Dr.) Toophan Kanti Dolai, HOD, Dept. of Haematology & Nodal Officer, Thalassaemia Control Unit, NRS Medical College & Hospital.
- 40. Chief Medical Officer of Health (all).
- 41. Dy. CMOH-II( All).
- 42. Superintendents of......DH/SDH/SSH.
- 43. Office copy.

Jt. DHS(NCD) Swasthya Saathi.

## SOP for rolling out of "Care and management for Haemophilia West Bengal".

Nodal Centre: IHTM, Kolkata.

State Technical Expert: Prof.(Dr) Maitreyee Bhattacharyya

State Nodal Centre: State NCD Cell, Swasthya Bhavan.

Facilities included – All Thalassaemia Control Units (34)

#### Checklist for each centre before starting the program:

#### A. Staff:

- I. Medical Officer-01
- II. Lab Technician-02
- III. Counsellor-02
- IV. Staff Nurse-02
- V. Data Entry Operator-01
  - a. For 24 TCU facility:- Contractual TCU HR will be trained to deliver the service.
  - b. For remaining 10 TCU facilities (where separate contractual HR not approved by GOI):- Principals / Superintendents to be requested by order to identify the staff for each category.

#### **B. Equipments:**

- I. For Nodal Center:
  - i. Automated Cell Counter
  - ii. ELISA reader
  - iii. Automated coagulometer
  - iv. PCR
  - v. Sangers sequencer
  - vi. Computer, printer.
- II. For Peripheral Centers:
  - i. Automated Cell Counter. ( available with the facility)
  - ii. ELISA reader ( available with the facility )
  - iii. Computer, printer, ( available with the facility )
  - iv. Semi-auto coagulometer (to be procured & supplied from state HQ where not available).

Software to be developed as an addition to the existing Thalamon soft ware(utilized for Thalassaemia programme) for patient registration & data keeping.

#### C. Work Plan:

- A. Nodal center
  - i. Factor assay.
  - ii. Review of pt once in a yr
  - iii. Inhibitor screen
  - iv. Assessment of joints.
  - v. Molecular study & prenatal diagnosis
- B. Peripheral Centers
  - i. Initial Coagulation Screening
  - ii. On demand / Prophylaxis
  - iii. Physiotherapy, dental check up & counselling will be done.
  - iv. Keeping records
- D. Training of the involved HR -( at nodal centre )
  - i. For MO: 2 days training.
    - D1 -Lecture class on diagnosis & basic management of Haemophilia. Exposure to lab procedure & interpretation of reports.
    - D2 -To attend Haemophilia OPD & day care for practical exposure to patients.
  - ii. For lab technicians: 2 days training.
    - D1 Lecture on diagnostic methods & procedure.
    - D2 Wet lab training of doing coagulation & factor assay.
- iii. For Counsellor: 2 days training.
  - D1 Lecture on haemophilia diagnosis & management (outline), Counseling In haemophilia.
  - D2 To attend haemophilia OPD of IHTM for training on how to fill up the Proforma in OPD, Practical counseling.
- iv. For Data entry operator: 1 day training.

D1-One day training at IHTM, how to enter data in software.

v. One day Sensitization trg. for all Physicians, Paediatricians, Orthopaedicians, Dental Surgeons & MOs of the facility who perform Emergency Duties.

#### Implementation detail:

- 1. <u>In all TCUs Thalasseamia OPD will be designated as "Thalassaemia & Haemophilia OPD".</u> For this necessary signage & IEC to be displayed in the facility to increase the visibility.
- 2. Any haemophilia patient attending OPD will first go to the counsellor for recording detail of the patient in the Patient wise Record Sheet proforma (page-7 to 10). There after the patient will have go to the MO (trained) with the file, he/she will examine the patient & advise (keep all important findings in the Patient wise record sheet). All Patients will be asked to attend OPD every 2 months normally & or immediately for emergencies.
- 3. Physiotherapy to be arranged during one of this visit & patient will practice it at home.
- 4. In case of active bleeding, Patient can attend TCU (Office hours), Emergency (non OPD hours) to get factor.
- 5. Provision of factor from ER & a guideline of how much factor to be given to be kept/ displayed in ER.
- 6. All patients will be provided with "Identity Card with Unique ID" (sample in page-6) & a diary (follow up, page 11-14) where doctor will record the site of bleed & how much factor was given each time. Later on when the patient will attend at OPD, counsellor will record everything in the existing Case file from the diary.
- 7. Patients will be sent to IHTM once in a year normally for examination, evaluation & advice.
- 8. HBsAg/HCV/HIV to be tested every year.
- 9. Inhibitor to be tested every year.
- 10. X-ray of affected joint to be done once in a year.
- 11. Updated file to be sent to Data Entry Operator for entry in the software in real time.

## E. Patient with bleeding undiagnosed:

- i. Check platelet count.
- ii. Do PT & APTT ( before FFP ).
- iii. Give FFP for control of bleeding.

## iv. Send the patient to IHTM for factor assay.

## F. Guideline for Management of Acute Bleeding:

### Joint Bleed Diagnosis:

- i. Limitation of movement.
- ii. Pain.
- iii. Swelling & warmth.
- iv. Echymoses.
- v. Aura.

#### PRICE:

- i. Protection (splint),
- ii. Rest,
- iii. Lce,
- iv. Compression,
- v.  $\underline{\mathbf{E}}$  levation.

#### Technique of ice application:

- i. Put ice in a cloth & crush.
- ii. Apply on skin with a thick towel.
- iii. Keep on joint for 5 mins.
- iv. Remove for 10 mins & again apply.

#### Management of pain:

- i. Paracetamol.
- ii. Paracetamol + tramadolol.
- iii. NSAID contraindicated.

## Life threatening Bleeding episodes:

- i. Head
- ii. Neck
- iii. Chest
- iv. GI tract

Patients to be hospitalised.

Any patient with headache to be given factor first, then send to radiology for CT scan of brain. Then go for Clotting Factor.

### Dose calculation:

#### **Principles:**

- Baseline factor level in (Patient With Haemophilia) PWH is 0%.
- Need to raise the clotting factor levels to a **certain minimum level** that will stop bleeding -> **site of bleed**.
- ullet 1 unit/kg Factor VIII raise the plasma FVIII level approximately 2% .
- 1 unit/kg Factor IX raise the plasma FIX level approximately 1%.
- Factor VIII concentrates: dosage
  - o Dose calculation for number of units: [Body weight x **Desired level**]/2
- Factor IX concentrates: dosage
  - $\circ$  Dose calculation for number of units: Body weight x **Desired level**.

Site of bleed	Desired level
Muscle / joint	30-40%
Iliopsoas bleed	60%
Throat	
Neck	50-80%
GI	30-0070
Genito-urinary	
Surgery post-op	
Surgery Pre-op	
Intracranial bleed	100%

Site of Bleed	Dose	Duration
Joint	15 units / kg	1 – 2 days
Muscle	20 units / kg	1 – 2 days
CNS	50 units / kg	7 days
Throat and neck	30 - 40 units / kg	7 days
Gastro intestinal	30 - 40 units / kg	7 days
Renal	25-30 units / kg	5 days

Always round up the dose.

## How to administer factor:

- i. I.V slow push.
- ii. Factor VIII to be given twice daily but in case of OPD & Day Care management once daily is to be considered.

## Prophylaxis:

To be started to all children < 10 yrs of age & without gross deformities approx ( eligible for both primary & secondary prophylaxis ).

## Prophylaxis schedule: -

Low dose prophylaxis 20 units / kg, 2 times / wk.

Ou

আমি একজন <b>ইমো</b> ফিলিয়া (Hemophilia) রোগী। আমি হঠাৎ অসুস্থ বা দূর্বল হয়ে পড়লে, আমাকে সত্ত্ব হাসপাতালে নিয়ে যান।	INSTITUTE OF HAEMATOLOGY & TRANSFUSION MEDICINE Medical College 88, College Street, Kolkata-700 073 (W.B.) India. Ph:- 2212 3785
Type of Hemophilia  ● হিমোফিলিয়া সংক্রামক ব্যাধি নয়।	আমার বক্তির গ্রুপ আমার নাম ব্যাস

## Haemophilia Patients

## Data Entry

## **Form**

(PATIENT RECORD)

## **Initial Evaluation**

1.	Name of Patient :			
2.	Registration No :			
3.	Blood Group:			
4.	Age at diagnosis:			
5.	Family history of sin	nilar disorder :		
6.	School Performance	2:		
7.	Occupational Proble	ems :		
8.	Initial Presentation	:		
9.	Lab Evaluation:			
	i) Initial Level of	factor at diagnosis:		
	II) Type of Haem	ophilia :-		
Γ	Туре	Sever	Moderate	Mild
	Α	1		

11.	In	hil	sitc	rc	tat	115
11.			,,,,,	,, ,	·u	

12. Viral Serology status

В

a. HBsAg

b. HCV

c. HIV

d

13.	Clinical	Examination a	t the	time of	f reg	istration
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- a. Height
- b. Weight
- c. Dental Survey

#### d. Musculo skeletal Examination

Joints	Left	Right	Deformities	Tenderness	Musele		
affected	Side	Side		renderness		Movements	Others
	Jide	Side	present		Atrophy		
Knee							
Ankle							
TII.							
Elbow							
Wrist							
Psoas							
Hip					1		
Others							1

## 14. Target Joint:

Imaging

Joints	USG		
	330	x-ray Joint Finding	MRI
Knee			
Mice	75-0		
Ankle			
Elbow			
Wrist	And the second		
Psoas	Es ·		
Нір			
Others			
т .			

## 15. Treatment

Prophylaxis	On demand

## 16. Prophylaxis Schedule

## 17. On Demand Therapy:

## 18. Physiotherapy & Exercise:

## 19. Counselling:

- i) Genetic Counselling:
- ii) Prenatal History:
- iii) Carrier Detection:

## **FOLLOW UP SHEET**

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#### Follow Up

#### Clinical

Date	Ht. (cm)				SI	TE OF	BLEED	ING				Treatment Given		n	Signature of the Doctror			
		Brain	Dental / Gum	Elb	Fore arm	Wri st	HIP	Psoas	Knee	Ankle	Others	FFP	Cryo	F- VIII	F- IX	Others	·	
															1			W 121 4 2
																	, a	
														+	+			,
														-	+			
												_	_	-	+	-		

### Lab (Annual Evaluation)

Date	Inhibitor	HBsAg	HCV	HIV

Imaging (Annual Evaluation)

Date	Joints	Xray	USG	MRI

(Annual Evaluation)

Date	Joint score

Year	ABR
	Aut

Joznin 19.

Director of Health Services Govt. of West Bengal.