

**REGION III HEMOPHILIA PROGRAM
GUIDELINES FOR PATIENT CHOICE POLICY
(MINIMAL STANDARDS)**

1. POLICY

The HTC's in Region III affirm that all patients and families have the right to participate actively in their care, including choice of hemophilia treatment provider, treatment product, vendor of treatment products, and home nursing services.

II. PROCEDURE

1. The HTC physician makes recommendations regarding type of treatment product after discussion with patient and/or family. The discussion, and resulting choice, will include considerations regarding safety, efficacy, price, insurance, availability, type and level of deficiency and individual treatment history.
2. Patient/family choice is documented on chart.
3. Education sessions concerning product choices are conducted at least yearly at times of comprehensive care visit to HTC. Updated information is provided regarding currently available plasma-derived and recombinant products.
4. Prices of the different products vary widely. We encourage patients to monitor charges and insurance coverage regularly. HTC staff are available for assistance with these issues.
5. All orders for treatment products should come from a Hemophilia Center physician.
6. A maximum of a three-month supply of product can be ordered at any one time. Home therapy records should be submitted prior to renewal of product orders.
7. As new products become available, patients and families will be notified in a timely manner and information will be provided to promote an informed patient choice regarding the new product.

B. DELIVERY OF FACTOR CONCENTRATES

1. HTC staff will present options for provision of factor replacement concentrates.

These options may include:

- HTC-related Factor Delivery System
- Commercial Home Care Company
- Hospital Pharmacy

2. Information provided by several home care companies will be available to patients/families. HTC staff will provide a list of some home care companies and will answer questions that arise. Patients and families will be encouraged to explore all home care options, and investigate coverage. HTC staff will provide suggested criteria which patients/families may wish to use in selecting a home care company.
3. Families will be informed that their insurance company may limit their choices.
4. When the patient/family has selected a vendor, that choice will be documented on the patient's chart.
5. If and when patient/family chooses an HTC affiliated home care vendor, they may be asked to sign a disclosure form, documenting free choice and knowledge of other vendors.
6. HTC staff will contact vendor, initiate referral and provide factor prescription.
7. Families should inform the HTC if their choice of product or home care vendor changes. All such changes will be documented on the chart.
8. The HTC reserve the right to delay delivery of needles and syringes until the family is certified in home I.V. infusions.

C. NURSING SERVICES AS RELATED TO HOME CARE COMPANIES

1. Home nursing services require a physician order. These services will be recommended when included in a plan of care developed with input from patient/family and HTC staff.
2. When discharged from the hospital, home care nursing services may be recommended for post-hospitalization care.
3. HTC or hospital staff will present home nursing options to patient and family.
4. Families will choose home nursing services considering convenience, availability and insurance limitations.

D. PATIENT AND FAMILY RESPONSIBILITIES RELATED TO HOME CARE SERVICES

1. Attend Comprehensive Care Visit at least yearly. This visit will include nursing and medical evaluation and may include physical therapy, social work, dental, orthopedic and genetic consultations.
2. Keep updated treatment logs and bring these to the annual visit or more frequently if needed. This allows HTC to alter your dosage of medication appropriately and identify problem bleeding sites.
3. Contact your HTC if you have a bleeding episode that is not responding to usual treatment or if you have concerns about you/your child's general well being.

4. Do not let your prescription run out.
5. You should educate yourself about the financial aspects of the product supplier. Ask many questions and particularly request information regarding price per unit, availability of products, lifetime and yearly insurance caps, out of pocket costs and always compare charges with the coverage.

E. NHF STATEMENT OF PRINCIPLES FOR HOME CARE DELIVERY (see attachment)

**F. NHF RIGHTS AND RESPONSIBILITIES (see attachment)
FACTOR CONCENTRATE DELIVERY SERVICES**

The following list of vendors is not all-inclusive and you may wish to consult the telephone directory for other available vendors. You may also wish to consult with your physician or other health care professionals before making your selection of a vendor.

Please find listed below certain criteria that you may wish to consider when selecting a home care vendor.

CRITERIA

1. Companies should provide 24-hour availability of services and products.
2. Companies should demonstrate a willingness to address and resolve problems brought to their attention.
3. Companies should provide a full range of services to meet the needs of the hemophilia community (pharmacy, delivery, nursing, financial counseling, etc.).
4. Companies are responsible for providing prompt communications to the hemophilia center concerning patient needs and changes in patient status.
5. Companies should keep adequate records of prescriptions and communications.
6. Companies should be fully accredited by appropriate state and /or federal agencies.
7. Companies should keep adequate inventory to meet patient needs both on an immediate and long-term basis.
8. Companies should demonstrate an appropriate level of knowledge regarding hemophilia and HIV necessary to provide the hemophilia community optimal care.

9. Companies should share with patients their policy regarding discontinuation of services related to loss of coverage or inability to pay.
10. Companies should provide the patient with the expected costs for medications and services provided. Deviations in cost should be reported to patient.
11. Companies should provide accurate data to the patient and the hemophilia center concerning shipment and usage of product, supplies, and adjunctive therapies.
12. Home care companies must inform HTC's and consumers of all product recalls and withdrawals within 24 hours.
13. Companies should not use gifts and free services unrelated to hemophilia care to induce you to choose them.

The above criteria are not all-inclusive but should assist patient and families in making their selection.

**Addendum to Region III
Regional Patient Choice Policy**

**The National Hemophilia Foundation
STATEMENT OF PRINCIPLES FOR HOME CARE DELIVERY
(adopted in 1988)**

a. To Industry

1. Non-center delivery system are encouraged to closely supervise their field representatives and seek guidance from centers for comprehensive orientation, training and evaluation program.
2. Marketing and distributions of product to patients should include the participation of a hemophilia treater from the patient's center. There should not be direct marketing to patients by non-center delivery systems.
3. In the interest of optimum patient care, all medical and psychosocial concerns regarding treatment and arising from direct contact between patients and field representatives should be referred to the hemophilia treatment center (HTC).
4. Patients should be encouraged to visit an HTC of their choice, or referred to an HTC if requested. All referrals to non-center physicians, nurses, social workers, and other health professionals should be coordinated with the HTC, with patient approval.
5. All industry representatives should develop ongoing relationships with local HTC personnel to review recommended patient and center treatment protocols. Patient confidentiality must be maintained.
6. All companies should send patient usage records to the HTC. Such records should include information on number of units, lot numbers, and brands of products supplied.

7. Companies are encouraged to continue their practice of dispensing and collecting log sheets. In addition, companies should require patients registered at HTC's to submit 100% of log sheets to the center.
8. Companies are encouraged to continue support of hemophilia-related activities.
9. Companies should require patients to attend their annual comprehensive evaluation at a hemophilia treatment center of their choice.
10. Companies should continue their practice of billing to third party payers.
11. Companies should not accept a direct orders for blood products from patients without the knowledge and advice from hemophilia treater.
12. Companies should stock and supply a full range of sizes of brands of products when requested. If sizes or brands of products are not available, companies should consult with HTC for physician recommendation.
13. Every effort should be made to supply blood products at lowest possible cost.
14. Adequate provisions must be made to provide blood products to patients who do not have third party coverage.
15. Patient confidentially should be requested and maintained at all times.

b. To Hemophilia Treatment Centers

1. Every effort should be made to supply the prescribed blood product at the lowest cost and to provide a choice of appropriate brands and sizes when possible.
2. HTCs should provide home delivery as an option to patients.
3. HTCs should increase accessibility of patient procurement of blood product to patients (including hours for ordering and delivery, and modes of delivery).
4. HTCs should educate their billing departments regarding appropriate billing procedures to recover optimum reimbursement for the cost of providing the product. HTC billing department should contact the HTC for collection problems in lieu of creditors.
5. HTCs should collect and analyze 100% of all log sheets as expeditiously as possible.
6. HTCs should provide information to patients with frequent updates on product choices, dosage revisions as necessary, and guidelines.

7. Formal home therapy education must be documented and precede the implantation of any home delivery system. Such education should be provided by a comprehensive hemophilia treatment center or a hemophilia treatment unit as defined by NHF.
8. HTC's should develop positive ongoing relationships with home delivery suppliers to evaluate patient care.
9. HTC's should develop written home therapy guidelines for both patients and the center.
10. Prescriptions for blood product should be reviewed periodically (6 months – 1 year) by the physician.
11. Patient confidentiality should be respected and maintained at all times.

C. To Chapters

1. Home delivery services are not a substitute for comprehensive care. Medical and psychosocial concerns should be addressed to the HTC.
2. Patients must complete all log sheets and submit them at least every 6 months to 1 year.
3. Patients should obtain center and Chapter input when choosing a delivery service.
4. Patients using non-center physicians, nurses or other health care professionals are encouraged to maintain contact with treatment center professionals.
5. Refill prescriptions for blood products should be made with the knowledge and advice of the HTC.
6. Patient should obtain all medical and psychosocial advice from HTC or their hemophilia treater.
7. Patients should become knowledgeable about price and reimbursement mechanisms, and coverage limitations of their own policy.

REGION III PATIENT CHOICE POLICY

(signed acknowledgement)

The HTC staff reviewed the HTC's Patient Choice Policy with me and I have had the opportunity to ask questions about the policy. I have received a copy of the policy.

Signature: _____
(Patient or family member)

Date: _____