

CHOICES AVAILABLE TO PATIENTS AND FAMILIES WITH HEMOPHILIA IN THE MOUNTAIN STATES (REGION VIII)

The following patient choice policy has been adopted for patients and families served by the Hemophilia Treatment Centers in the Mountain States Region (Region VIII). These include Centers at the University of Colorado at Denver and Health Sciences Center, the University of Arizona Health Sciences Center, Phoenix Children's Hospital, the University of New Mexico Health Sciences Center, the University of Utah Health Sciences Center and Primary Children's Hospital.

CLOTTING FACTOR

As a patient and/or family that receive care at one of the Hemophilia Treatment Centers (HTCs) in Region VIII, you have the right to choose the clotting factor that you feel is safe, effective and affordable. In some cases, your choice of clotting factor concentrates may be limited by your medical insurance or other payer. Hemophilia Treatment Center (HTC) staff is committed to advocate for you when there are unreasonable limits on choice or when HTC staff feel a specific clotting factor is medically indicated. The National Hemophilia Foundation's Medical and Scientific Advisory Council has stated that there is no "best" product that fits the needs of every patient.

HTC staff is also committed to ongoing education of the persons with hemophilia about existing clotting factor products, the introduction of new treatment products, and current and upcoming shortages and discontinuation of products. This information is updated during hemophilia comprehensive clinic visits, by mailings to your home, telephone calls or home visits, or during camps and hemophilia chapter meetings. Together with your physician, you may then make an educated and informed decision regarding the products you wish to use.

When evaluating an infusion product, we suggest considering the following issues:

ISSUE	QUESTIONS	QUESTIONS
Method of manufacture	Recombinant technology or plasma derived?	
Purity	Does it contain other proteins	Is animal protein used in manufacturing process?
Viral inactivation methods	Solvent detergent?	Heat Treatment?
Efficacy	Does it work for controlling bleeding	Do recovery studies show predicted factor levels?
Data available from well-conducted studies with this product	Any adverse effects from the product?	Are there special requirements for use and storage?
Cost	Are the benefits of using a newer or more expensive product worth the extra cost?	Are there any proven benefits for using a more costly product?)
Volume of treatment product	How much volume is the product for infusion?	

The HTC staff is always available for consultation regarding product use and choice.

HOME CARE

You and your family are encouraged to select a home delivery company with whom you are comfortable, although this choice may be limited by your third party payment sources. Center staff can provide a list of available home delivery companies and you are strongly urged to compare prices and services. As you know, clotting factor is very expensive and there may be a considerable "mark-up" of prices by different home care companies. This makes the sale of factor very profitable for home care companies and their stockholders. We encourage you to become a knowledgeable consumer of these expensive medications, to know the cost of your clotting factor and to remain aware of your lifetime insurance limits. It is in all of our best interests to keep the cost of clotting factor as low as possible by negotiating prices and services with insurance and home care companies or choosing companies that offer both good service and pricing. Your Hemophilia Treatment Center can be a helpful resource for information regarding home care.

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You and your family should consider some of the following criteria when selecting a home delivery service or discussing the choice of home delivery service with your insurance company, case manager or Medicaid or Medicare plan. The chosen company should

- 1. Have 24-hour availability of products and services and emergency access to product.**
- 2. Demonstrate appropriate and adequate knowledge of hemophilia in order to provide optimal services.**
- 3. Provide a full range of services to meet your individual needs including pharmacy, delivery service (including rural delivery) and financial counseling.**
- 4. Provide communication with the HTC about any critical or emergency needs you might have, about any problems with inventory and any changes in your health or insurance status.**
- 5. Keep complete records of your prescriptions, billing and communications.**
- 6. Keep adequate inventory for your short and long-term clotting factor needs.**
- 7. Be fully accredited by the appropriate state and/or federal agencies.**
- 8. Demonstrate willingness to resolve problems brought to their attention.**
- 9. Make you and your family aware of company policy regarding discontinuation of services related to loss of your insurance coverage or your inability to pay for services.**
- 10. Provide you with expected costs of medications and services.**
- 11. Promptly report changes in costs to you.**
- 12. Provide accurate data to both you and the HTC regarding shipment and use of products, supplies and adjunctive therapies.**

COMPREHENSIVE CARE

As a patient/family with a bleeding disorder receiving services from the HTCs in Region VIII, you have the right to receive comprehensive hemophilia care. If requested, you may be given choices regarding different components of comprehensive services and at times you may elect to forego certain components or see additional providers outside of the HTC. Every possible consideration is given to scheduling the visit at a time most convenient to you and your family. Assistance in arrangements for transportation and accommodations for families traveling long distances to the HTC is provided as necessary. The HTC is committed to advocating for insurance authorization for comprehensive clinic visits if your payer denies them.

PROVIDERS

You have the right to choose a primary and secondary provider as dictated by convenience, culture, insurance and practicality. Each HTC provides comprehensive care to patients who have primary physicians in the community as well as those who receive primary care in our institutions. HTC staff is willing to work with and consult with any health care provider involved in your care. However, consultation is an adjunct to and not a substitute for comprehensive care. Communication with your primary care provider regarding comprehensive hemophilia care and HTC recommendations is of the utmost importance to facilitate coordinated and optimal hemophilia management.

CONSENT

As a patient or family receiving care in an HTC in Region VIII, I acknowledge that HTC staff has discussed options and choices available to me or my family concerning clotting factor and hemophilia treatment products, home care vendors, comprehensive hemophilia care and primary and secondary health care providers. My signature acknowledges that my choices are made freely. I understand that I may contact HTC staff at any time to discuss any issues related to these choices and that I can expect HTC staff to advocate for my best interests.

Patient _____

Signature of patient, parent, or legal guardian _____

MSRHC staff member _____

Date _____