

Policy Statements – Patient Choice

Being cared for by the Mary M. Gooley Hemophilia Center is voluntary and it involves making choices that may affect your or your child's well being.

Taking good care of someone with a chronic condition requires informed, capable participation by the affected individual and his/her family (however they define their family). Below are policy statements regarding three important choices patients may face here at the Center. Please review our entire policy and ask questions.

NOTE: To the extent practical, a patient's choices will not impact services or products provided by the Center nor the patient's ongoing relationship with the Center.

POLICY STATEMENT – Choice of Health Care Provider

If asked, the Center will make every reasonable effort to meet a patient's request that they be seen by / treated by specific healthcare team members. Such requests are not always possible to fulfill and are not the Center's primary concern. The Center's primary concern is the health, safety and well being of all our patients. We have confidence in all the people on our team.

POLICY STATEMENT – Choice of Specific Clotting Factor Product

Patients will have access to the full range of FDA-approved factor therapies indicated for their condition. Informed, individualized decisions about particular products are to be made within the provider-patient relationship. Criteria which may help determine the choice should include the patient's safety, medical history, condition and need, anticipated efficacy (how well it will work), product availability, product half-life (how long it lasts), cost and restrictions (if any) imposed by healthcare payers and regulators.

POLICY STATEMENT – Choice of Clotting Factor Supplier

Patients may obtain clotting factor from any qualified supplier. In addition to many Hemophilia Treatment Centers, sources for factor may include home care companies, specialty infusion companies, some pharmacies, some hospitals and other specialty distributors.

The Center requires that for patients using clotting factor:

- 1) the patient must supply the Center with an accurate record of factor infusions done and their home inventory at least every 30 days;
- 2) the patient must attend a "Comprehensive Care Clinic" at the Center at least once annually;
- 3) the supplier selected must meet known requirements ("Standards of Service" guidelines approved by the Medical and Scientific Advisory Council of NHF - MASAC Document #188 – available upon request); and
- 4) it shall not be the Center's role to arrange for an alternative supplier and patients shall inform the Center of changes.

- PLEASE REVIEW THE FULL POLICY AND ASK QUESTIONS -

(Available from the Center)