NATIONAL HEMOPHILIA FOUNDATION
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MASAC Document # 227

MASAC RECOMMENDATION REGARDING HOME FACTOR SUPPLY FOR EMERGENCY PREPAREDNESS FOR PATIENTS WITH HEMOPHILIA AND OTHER BLEEDING DISORDERS

The following recommendation was approved by the Medical and Scientific Advisory Council (MASAC) on April 13, 2014, and adopted by the NHF Board of Directors on June 5, 2014.

Background

Patients with hemophilia and other bleeding disorders require immediate availability of factor concentrate in the event of an emergency. All patients with hemophilia, regardless of whether they are on home treatment or not, need an emergency supply of factor for self- infusion or to take to the nearest emergency department or medical facility. Unfortunately, insurance companies and Medicaid are limiting the amount of factor a patient can have at home or denying refills until patients are down to the last 2 doses. This practice places the patient at risk for severe and continued bleeding in the event of an emergency because it does not provide families with enough factor to cover a serious bleed over a long weekend or when a natural disaster makes it impossible for factor deliveries to occur in a timely manner.

Hurricane Katrina provides an example of the difficulties encountered in a natural disaster. The accompanying document entitled "Background Information" details the responses of CDC and NHF to this disaster and their successful efforts to provide medical information and factor for patients displaced by the hurricane.

In Utah, California and other states, there is a concern about the effect of a major earthquake. The "Background Information" provides some thoughts on this issue.

The "Background Information" also delineates the difficulties with Medicaid that are being encountered in Michigan.

MASAC Recommendation:

All patients with severe and moderately severe inherited bleeding disorders for whom clotting factor concentrates (CFC) are available should have 7 extra doses (special consideration of number of doses for inhibitor patients) of the CFC at home to be available in the event of an emergency. The dose should be based on the factor level to achieve a hemostatic level of 100%, rounded up to the nearest vial size. The dose and frequency should be determined by the patient's health-care provider.

Individuals should consult the FDA Emergency Preparedness website:
http://www.fda.gov/EmergencyPreparedness/ **for additional information on emergency preparedness.**

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BACKGROUND INFORMATION TO MASAC DOCUMENT ON EMERGENCY SUPPLY OF FACTOR IN THE HOME

Recent experiences with factor shortage: Hurricane Katrina
CDC role: Mike Soucie:
"After Katrina, we used the zip code data on patients participating in UDC to identify hospitals and ERs in the vicinity of patients and sent material to those locations that informed hospital and ER staff where patients who came to them for care could get access to factor and specialized care. Dr. Cindy Leissinger in New Orleans had set up an alternative site and as already mentioned the Houston center also helped out. We provided this information along with contact information for those medical sites for consultation needs."

NHF Role: Neil Frick:
During Katrina we worked with the pharmaceutical companies to donate factor to the displaced people that went to Houston. Dr. Keith Hoots in Houston would let us know when he was treating patients from New Orleans and how much factor they used and we would have the pharmaceuticals send that donated factor to Houston. We also worked with Hemophilia of Georgia to get treatment for people that were displaced from other states besides Louisiana. We also posted emergency information and referrals on our web site, we made sure that our HANDI line was being checked 7 days a week so that we can help refer patients and we also created a brochure on an emergency family checklist.

Utah example: Earthquake Heidi Lane:
An earthquake is the primary concern and could prevent ground transportation for weeks up to months. The airport is expected to be inoperable for weeks up to months. Local supply is limited to 3 homecare companies with minimum par levels. Injury rate is expected to be high by nature of the natural disaster being an earthquake. Utah HTC feels, ideally, a month supply is preferable for patients with severe hemophilia and a minimum of a 2 weeks supply is recommended. Insurance providers prevent storage of adequate factor to be prepared for a natural disaster in Utah. ATHN has a program that provides the patient's medical record information on a flash drive that patients could give to emergency medical personnel. In Utah, we are not permitted to use this system due to institutional restrictions.
Michigan example: difficulties with Medicaid
MSU Experience: Laura Carlson:
"It has been our experience that we have had the most difficulty with Medicaid regarding limits on factor dosages in the home. For a person using factor episodically, Medicaid will only allow 5 doses in the home total for any period of time. That means that if they have 3 in the home, only 2 will be approved. If the patient is treating three times/week and the prescription is written with those directions and as needed for bleeding, they will allow 12 prophylaxis doses with 3 extra bleed doses for 1 month. When reordering, if the patient still had 3 doses left, they would only allow the 12 to be sent for the month.

I have spoken to several pharmacists who relate to this experience but added that they have noticed the most change with Michigan Medicaid and BC of Illinois. Also if there is a third party managed care such as Icor (was used previously for Michigan Medicaid) the dose also had to fall within a very tight range almost making it impossible to dispense from inventory. Patients would have to mix vials, extra lot numbers would have to be ordered making stock larger or treatment centers would have to rewrite prescriptions to meet the exact dose that was in stock."