



## Hemophilia Federation of America

Advocacy For Persons With Clotting Disorders

March 30, 2007

Susan G. Queen, Ph.D.  
HRSA Reports Clearance Officer  
Room 10-33 Parklawn Building  
5600 Fishers Lane  
Rockville, Maryland 20857

Dear Dr. Queen:

Re: FRP reporting as stated in FR Vol 72, No. 24

The Hemophilia Federation of America is a national nonprofit organization that assists and advocates for the blood clotting disorders community. In the role of advocates for this community, HFA is very interested in the outcome of this project.

The Hemophilia Federation of America is pleased to provide comments regarding the need for and requirement to provide important data from each Hemophilia Treatment Center (HTC) that operates a program to sell factor replacement product. HFA has been asking for this type of information for a long time to determine whether or not these programs are really providing the financial relief they were supposed to for the HTCs and the benefit to the patient that was promised.

It is the understanding of HFA Board and Staff that the type of information you are proposing to request is basic for any grantee in reporting back to the grantor. As important as these programs can be to patients, HFA feels they must be fiscally responsible and this would include reporting of the type of data MCHB is requesting.

**MCHB Response:**

*MCHB acknowledges that the Hemophilia Federation of America (HFA) is in favor of the proposed data collection.*

HFA hopes that when this data is collected, it will be made available to the national organizations that advocate for the community and their chapters and member organizations.

**MCHB Response:**

*The HFA hope that data from the proposed data collection will be made available to the national organizations that advocate for the community and their chapters is subject to Freedom of Information determination. HRSA/MCHB will not release information to the public regarding individual grantees including individual HTC's in the absence of such determination. Any request for these data will be forwarded to the HRSA Freedom of Information Officer. MCHB will cooperate with the HRSA Freedom of Information Officer in providing any needed program information. A description of the Freedom of Information Act (FOIA) including HRSA and MCHB contacts can be found at:*

*<http://ontranet.hrsa.gov/Communications?FOIA.asp>*

Sincerely,

Jan Hamilton  
Advocacy Director

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