

EQUAL VOICES

Advocacy & Support For The Cleveland Ohio Sickle Cell Community

229510 Euclid Avenue
Euclid, Ohio 44117-1624
(216) 481-8479

ACBSA Meeting
12 June 2010

Mr. Chairman, Members of The Advisory Committee,

As an original community member of the Advisory Committee On Blood Safety and Availability I would like to take this opportunity to speak on behalf of our members in Cleveland, Ohio.

We appreciate the opportunity to comment on the possible change in the policy concerning Donor Deferral for Men who have had Sex with another Man. As a former member of this committee, I fully understand the delicate balance between availability and safety. I also understand the responsibility each member on this committee has in regards to the history of the blood supply in this country. We are here as members of Equal Voices. Equal Voices is a non-profit group that works with individuals with Sickle Cell, Thalassemia, Hemophilia, HIV and other genetic disorders. We work locally in the City of Cleveland with a sickle cell support group called Kinkaid's Kindred Spirits. Equal Voices was initially created to assist individuals and families with sickle cell disease, this came about due to a lack of social services, resources, and educational material available to sickle cell patients. We have since adapted our mission to include any blood born illnesses and all genetic disorders.

Sickle cell disease affects millions of people of all races. Sickle cell is found in Africa, The US, Central and South America, the Caribbean, Saudi Arabia and throughout the Middle East, Italy, Greece, and many other countries spread all across Europe and the rest of the world. The United Nations had recognized sickle cell as a public health priority and has recognized June 19th as world sickle cell day, yet still, people do not know about the disease. There is especially a lack of knowledge within the African American community.

The United Nation estimates of seventy to one hundred thousand people with some form of sickle cell disease in the U.S. and we estimate that there are over one million people in this country with the sickle cell or thalassemia trait. Within the next two decades there are estimates that there will be more Hispanics than African Americans with sickle cell disease in this country. Sickle Cell patients need constant care; they are hospitalized regularly for severe debilitating pain. Treatment consists of, intravenous hydration, Pain management, and blood transfusions. A normal person's red cells last 120 days, a sickle

cell patient's will last on average 46, a third of the lifespan. This underlines the sickle cell community's dependence on a safe and available blood supply. The blood they require on a weekly basis replaces blood destroyed during a crisis, and can help shorten the duration of a pain episode. For severe sickle cell patients chronic transfusions are the norm. This type of treatment means transfusions may occur every two to four weeks for an indefinite period of time. The sickle cell community has had a difficult time over the last 50 years in terms of access to proper care, disease education, a consistent standard of care, as well as the lack of data regarding HIV/AIDS, and hepatitis C transmission rates among sickle cell patients.

We are concerned that these issues will deteriorate at a greater rate due to communications and cultural differences and lack of trust in the medical community. The majority of the Sickle Cell community is unaware of the devastation that occurred to the Hemophilia Community, they are unaware of the actions of our government and the blood collecting agencies that led to this tragedy. With the hemophilia community losing almost half of its population, and with many of the other blood user communities unaware of this occurrence, it is a tragedy within itself, and the fear of a repeat event requires this committee to move cautiously and expeditious.

The sickle cell community understands the need for more donors. We are also losing patients due to the inability of the blood centers to obtain the specific type of blood needed. But we ask for caution with any change in the deferral policy. Until there is a change in the way some centers conduct business we will be concerned. When it is cheaper to pay the fines of associated with a government imposed consent decree than cleanup the problems, we all must continue to be vigilant. We must also accept that this type of behavior sends the wrong message to the end user. All one must do is look at the recently recalled blood related products to understand that we are still working within an imperfect screening process. The balance between availability and safety is a delicate issue that can have tragic outcomes once again if we lose sight of the trust the end user must have if they are to be an equal partner within this equation.

As an end users who receives regular transfusions, the sickle cell community has a stake in this matter, and we ask that this discussion on change is considered with the understanding that other components in this process of blood collection must be addressed in order to ensure the safety of the end user; including any high risk behavior from people in all donor communities, especially where risky behaviors has resulted in high HIV transmission rates. This deferral should never have been about just gay men, this deferral should have been about any individual with high risk behavior. It is unrealistic to expect someone living a high risk lifestyle to abandon that behavior for a year simply to give blood.

Thank You.
Larry, Michelle, and Michael Allen -Equal Voices