Steven Sepe

From:

Tina Massimino

Sent:

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To:

House Health and Human Services Committee

Subject:

Testimony H-5864

Representative Lima would like this testimony submitted for the Committee hearing today (3/13/25) regarding H-5864. Thank you.

Testimony in Favor of HB5864. My name is Liz James and I am a pharmacist and President and founder of a 100% volunteer cooperative, Blessed By His Blood, which matches known donors and recipients throughout the United States. I am testifying on behalf of myself and this organization.

The right to directed donor blood or autologous blood donation is a fundamental aspect of Medical Freedom and personal liberty for which every person should inherently have without question, and yet, it is becoming harder to accomplish because this right is quietly being either turned off or denied at time of need. The patient is in a vulnerable place, and they often do not have the time or physical energy to fight for their right to ensure that their health care decisions are carried out, as jointly decided upon by themselves and their doctor.

People choose directed donor blood for several reasons. Most importantly, all people should have the right to choose what they do or do not introduce into their own body.

Choosing autologous or directed donor blood allows for an increased measure of quality and safety for a patient AND gives the patient greater personal authority over what is entering their body, as well as a sense of peace. This is especially important in a time when a person is already stressed by the medical crisis they are actively walking through. Studies have repeatedly shown that increased stress also increases time to heal and recover.... the exact opposite of what healthcare should strive for.

According to the Red Cross website a limited number (12) of bloodborne diseases are screened for. This standard is issued by the FDA and followed by all blood banks. Due to this limited number, donated blood products remain a potential source of bacterial, viral, and parasitic transmission. It is important to note that ALL blood (both directed and anonymous) are screened for these diseases.

Additionally, while the FDA's guidelines for blood donation does include excluding donors with a history of drug use or addiction, the screening process of the blood itself does not include looking for illicit or prescription drugs within the blood. Unfortunately, there are many blood donation centers which advertise "gift cards or dollars for donations" and are located in lower income areas which may have a higher incidence of illicit drug use, and frankly, people don't always tell the truth. Anecdotally, we have heard many patient / patient family stories concerning secondary issues arising after an anonymous blood donation.

Once blood is in a bag, it has a "shelf life" of 40-50 days. One of the first components of blood to degrade is hemoglobin. Hemoglobin is necessary to transport oxygen efficiently throughout the body. When someone is in a healing crisis, one of the most important mechanisms of healing is having a well oxygenated blood supply. Because blood is a commodity, hospitals and transfusion centers typically use the oldest matching blood first for a client, so as not to waste the bag due to expiration. However, in a "known donor" situation, the blood a patient receives is usually less than a week old, which makes for a hemoglobin rich product and therefore is a superior product which is more able to transport oxygen to tissue in need of healing and recovery.

I'd like to also bring these points to you:

• The doctor writing the designated donor order is practicing medicine within his/her scope of practice and honoring their patient's beliefs.

- Both autologous and directed donor blood are legal, safe, and have a decades long history of prior use.
- The 14th Amendment of the Constitution (Section 1), which provides protection of a person's life, liberty, and property and due process of law is being violated.
- Also being violated is the The Patient Self-Determination Act of 1990 which affirms the common-law right of self-determination as guaranteed by the 14th Amendment of the United States Constitution. The person receiving care has the right to make choices and decisions about their medical care and the extent of medical care that they would or would not want.
- Additionally, The United States Commission on International Religious Freedom protects a person's right to freedom of thought, conscience, and religion or belief.

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Thank you for your time. I would be happy to answer any questions.

Stories of families (who we have personally worked with) who were denied the right to choose directed donor blood. These are a sampling of real life experiences which have occurred just within the last 18 months throughout the United States. (The italicized statements are the parents or patients own words):

- 8 mo old daughter is 'transfusion dependent' due to an inherited blood cell defect. Has had 9 transfusions, 4 of
 which resulted in 'transfusion reactions'. When signing blood product consent forms, there are 3 categories
 present: donor blood, direct donor or autologous donor. Mom asked about directed donation. Per MD/PA: PHR
 does not allow/participate in direct blood product donation at this time.
- Needed transfusion after giving birth; requested directed donation. Hospital refused, saying blood needed to be donated 72 hrs prior to use but 'refused to take a collection that she may use 3 days from collection'. Then, Pediatrician refused to do circumcision b/c baby wasn't vaccinated; finally agreed to do procedure but wanted mom to sign form that she'd accept 'their stored blood' if baby needed it or 'they won't perform the procedure'. She again petitioned for directed donor (circumcision was 2 wks away) & they told her there 'wasn't enough time to process the blood'.
- MD told our client 'they don't do directed donations anymore'. Stated she wanted to sign form refusing any blood; MD stated if she required blood, she 'would be left on table to bleed to death'.
- Parent of child in need was put off for weeks re: trying to get an answer about the directed donor process (go here to get paperwork, need to talk to this person, we don't do them often, too hard to coordinate, etc). \$750/transfusion. Was finally told it needed to be coordinated 10 days in advance. While being coordinated, Hershey Hospital called to tell them they wouldn't accept directed donation for this child because 'it was too complicated to set up.' Later transferred to Children's Hospital of PA. MD there said they would accept directed donation & that that hospital works with ARC. Parents started paperwork but ARC never followed up with them. Transferred again, this time to Sloan. By this time, parents too discouraged to try directed donations. Child has had 3 transfusions; praying he will be protected after receiving them. Problem is not cost or willing donors. Problem is that hospitals don't have a streamlined process AND are resistant to the idea. MD's willing to write the order & blood banks willing to collect donations. Hospital admins are the problem. The hospital and donation centers all wanted to know our 'why'. 'Why do you want a direct donation?' Our standard answer was, 'We want to know and control where and who the donation is coming from'. We got some resistance from this, but it ended with, 'The medical Director has to approve of your reason in order for us to proceed'.
- Needed open heart surgery. Asked Auburn hospital about directed donation but didn't get any clear answers. Had
 15 donors ready to give. Initially, surgery wasn't planned so no MD order. Transferred to Sacramento & surgery
 was scheduled. Tried to get directed donors lined up but needed surgery too soon. Only needed 72 hrs to get
 blood processed but they were told it needed to be donated 7-10 days in advance. Vitalent (blood bank) only
 draws blood on W & Th. Charges donors \$500/unit. Another person contacted Vitalent too but also got
 conflicting info. MD wasn't comfortable waiting # days needed to process blood so she had to accept 1 unit
 'regular' blood.
- MD ignored requests for & refused to discuss directed donation. Patient chose to live with his condition rather than accept blood donation from unknown source

- "My 1 year old son was diagnosed with acute myeloid leukemia in September, and his immediate needs in the hospital were blood and platelets. My husband is a frequent blood donor, and their blood types are compatible, and they would not let him donate to our son. The MDs are pediatric oncologists in chapel hill, NC. Some of them said it was because in the past, people have lied about having HIV, etc. when doing directed donations. That doesn't make sense to us since they test the blood donated and supposedly "clean" it. Some doctors said that the blood bank just didn't have the ability to store it and keep track of it for a specific person. My husband hosted two blood drives, and we had numerous friends and family members also wanting to give our son directed donations, and we told them we couldn't. On one occasion, the blood bank in the hospital was out of platelets when my son needed them, and on another occasion, they gave my son blood one day and again the next day, and they said they gave him less than he needed the second time because they still had some left from the same donor, so that could minimize his risk of reaction. If they could keep track of that, why not bank our family members' and friends' blood for him?"
- "My daughter was in the hospital at TMC in Sherman Tx they along with the hospital the Drs and Texoma Blood center said there is no possible way to choice any blood you can receive except whatever is in the bank. When I called and asked the blood bank about clean donations they stated "there is no such thing"!!
- "My son is 4 years old with a hole in his heart that needs to be repaired. We are in Washington state and the only hospital that does it here is Seattle Children's hospital. We requested directed blood donation for my son during his surgery and were rejected by the hospital (and [blood donation center] Blood Works). This will force us to go out of state and find a hospital that does this surgery as well as directed blood donations. I have contacted many children's hospitals all over the country and it seems we will be going to Ohio for the surgery. I'd love to do it right here in my own state. I don't understand why a hospital WOULDN'T do that for someone."
- "We were denied direction donation blood by St. Alphonsus Medical System in Nampa/Boise, Idaho as well as the Red Cross of Idaho/Utah. Yet, a different Red Cross in a different region but same state, allowed directed donations. (N Idaho good; S Idaho bad). "
- "Our daughter was born with two congenital heart conditions that can be resolved with surgery. Fortunately for us, her first surgery did not necessitate a blood transfusion. Her second heart surgery, however, requires that she go on a bypass machine. Because she is so small (she will turn one at the end of May) it is highly unlikely that she can use her own blood to prime the bypass machine. We live in Colorado, and originally planned to have the PAPVR repair at Children's Hospital in Aurora, near Denver. When we asked about coordinating a directed blood donation, we were met with nothing but staunch opposition. No one at the hospital would advocate for us. The assistant director of the blood bank would hardly even listen to my concerns about a random blood donor, and instead lectured me on the dangers of directed donations (even though we would provide a donor in a reasonable amount of time who is not a direct relative of my daughter). After reading about a family in Spokane whose child died after being given blood from a random donor because the hospital neglected to process the directed blood donation in time, we decided to pursue having our daughter's surgery at another hospital in another state. We currently plan to have her surgery at Nationwide Children's Hospital in Columbus, as they have no problem with directed blood donations."

As you can see from the sampling of stories all across the United States, this is a very real problem within our medical system leading, in some cases, to people delaying or doing without medical care because their beliefs are not being honored.

Our organization (Blessed By His Blood) is 100% not for profit. We are a cooperative member owned community throughout the United States, and are 100% volunteer driven. We have no financial advantage if HB5864 passes.

Thank you for your consideration and support of HB5864 and the right to bodily autonomy.

Respectfully, Liz James



Liz James

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[&]quot;Greater love has no man than this, that a man lay down his life for his friends." John 15:13