



Why is protecting the right to choose whose blood you receive a worthwhile medical and personal freedom to protect legislatively?

- Nobody imagines needing blood..... Until they need it, at which time, there is very often little time to fight for your right to choose what goes into your body, and certainly not a lengthy legal fight.
- Choosing autologous (self blood donation) or directed donor (known blood 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.
- According to the Red Cross website a limited number (12) of bloodborne diseases are screened for. Due to this limited number, donated blood products remain a potential source of bacterial, viral, and parasitic transmission.
- 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 "dollars for donations" and are located in lower income areas which may have a higher incidence of illicit drug use, and 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.

Is there currently a problem procuring directed donor blood even though it has been common practice for decades? YES!

- While directed blood donations have been around for decades, it is becoming increasingly difficult to ensure that a patient's (blood donor recipient) desire to receive "known donor" status blood is actually achieved, EVEN with a doctor's written order.

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- Most frequently, this basic patient right is being refused at point of service (eg: hospital, clinic, or donation /transfusion center), and the decision to refuse is being made by the blood donation corporate entity. Occasionally, there may even be a doctor who refuses to write an order for directed donor blood despite the patient's wishes.
- We first became aware of blood bank corporations quietly shutting down the right to choose whose blood you receive in 2023. When these facilities deny the patient's right to directed and autologous blood donations, they are also effectively overriding the doctor's written order, and the medical decision jointly made by the doctor and their patient. The FDA has quoted on their own website: " while a blood supply with zero risk of transmitting infectious disease may not be possible". It is extremely important to the Medical Freedom of every individual to have the choice of whose blood they receive. A patient receiving a directed donation will be much more likely to receive hemoglobin rich, fresh clean blood from someone they know and trust than from an anonymous source who may be on several medications or illicit drugs, and/or have lifestyle habits which may not be conducive to a healthy donation for a recipient in need.
- The blood industry is a multi-billion dollar industry. And although blood is usually given in a spirit of altruism, the blood market is quite lucrative and collected blood often doesn't stay in the community it was donated for. Blood is graded and profitably sold overseas, to research facilities, and to pharmaceutical companies for use in the production of many types of biologic pharmaceuticals. Conversely, when a directed donor's blood is collected, the donation is specific for the recipient according to a doctor's written orders. This means that this particular bag of blood is not eligible for sale to these outside markets, effectively eliminating the opportunity to make a larger profit than they might otherwise make through the hospital/ insurance avenue in a local use situation.
- We are aware of blood donation organizations shutting down the right to choose a directed donor blood supply throughout the nation. Perhaps the largest organization that has been working since July 2024 to deter attempts to direct donation is the American Red Cross (ARC). ARC is now requiring a "risk acknowledgement" form to accommodate designated donations in select regions of the USA. They are requiring that the doctor who wrote the order for directed donations (on behalf of the intended recipient) to now verbally counsel each

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DONOR on the risks associated with donating blood prior to them being allowed to donate. (We would like to ask, why is this a requirement of a known donor but not of an anonymous donor?) Doctors do not have the time to do this donor by donor, nor do they have a personal dr/patient relationship with that donor and many do not feel they have the doctor/patient relationship with that donor to even have the conversation.

- While the above situation is specific to the American Red Cross, there are also other organizations who are also working strategically to shut down the “directed blood donation” conversation. This video: <https://www.youtube.com/watch?v=tBNU7YdPNV4> is a training video for blood donation centers medical personnel, and it speaks directly about working to shut down the right to choose direct donors. At about the 34:00 minute on the training video, there is a discussion regarding Texas’s 2023 SB1584 and the blood industry corporation's need to prevent/halt bills protecting directed donations. Later, at about
- the 35:20 mark in the video, they talk about actively shutting down a similar bill (HB163) in Kentucky.
- In other situations, recipients are being charged excessively for utilizing directed donor blood as a way to deter someone financially from directed donations. We are aware of several situations where recipients have been charged \$500 to \$750 or more per unit of directed donor blood, in excess of what their insurance would have normally covered for anonymous pooled blood. There is minimal "excess work" warranting what could end up being several thousands of dollars if a patient needs multiple units of blood.
- In Texas, Carter Bloodcare, which serves the largest population in North Texas (over 200 hospitals and transfusion centers including every Children’s Hospital in the region), shut down the patient’s right to choose whose blood they receive at every facility they are contracted with in April 2023.. This means that patients who are determined to choose whose blood they receive must leave their doctor and their local care facilities (if they are able to) and travel a greater distance to receive the healthcare they desire. This scenario could happen in any state which does not have protective legislation, and leaves doctors and their patients at the mercy of the corporations making decisions based upon profit, not the best interest of the patient.

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Is denying the right to choose whose blood someone receives also denying a basic human right? We believe the answer is yes. Please consider these points:

- 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.
- In some state Constitutions, there may also be verbiage that also reinforces this right (ex: Wyoming's Constitution, Article 1 Section 38: Each competent adult shall have the right to make his or her own healthcare decisions. The parent, legal guardian, or legal representative of any other natural person shall have the right to make health care decisions for that person. (furthermore) The state of Wyoming shall act to preserve these rights from undue governmental infringement

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.

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- 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

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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). "

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- "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 when the right to choose directed donor blood is protected.

Thank you for your consideration to sponsor a bill in your state and be an advocate for Medical Freedom! Please feel free to contact me if you have any questions.

Respectfully, Liz James, RPh
Founder/Ceo

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